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**Patient treatment as
enactment: Knowledge
sharing across professional-
lay divides**

Master thesis

60 credits

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Abstract

This thesis has two main aims, investigated in three research questions. The first aim is to investigate first how hospital professionals, like secretaries', nurses', and doctors', knowledges is accomplished, used and distributed within the professional network, and secondly how information technology is used in these knowledge processes. The second aim is to look into how patients and parents interests are taken into account when performing treatment. The setting is the expert hospital Rikshospitalet, and the department of neurosurgery. An interpretive approach was used where interactions between hospital professionals, patients and parents were observed, and interviews performed later. The analysis is performed using aspects from knowledge theories like knowledge in practice, communities of practice, the difference between scientific and lay knowledge, as well as philosophical-historical elements related to the clinic. These aspects are analyzed using the theoretical framework of Actor-Network Theory (ANT). ANT enables an understanding of the treatment process as a network of action across different communities. The treatment is a relational process where different actors with different knowledges meet in order to attach necessary resources and perform treatment. The process is about obtaining partial alignment by taking into account different types of knowledges. If the doctor, and other clinicians, is able to see and understand the patient's interests, and take them into account, it may improve treatment processes. Three different aspects are analyzed. First, the structure of success in the treatment process relates to the ability that the doctor has to switch between different ontological perspectives. If he is able to understand and integrate the patients' interests, the enrollment succeeds. A second aspect regards what happens when the enrollment strategy fails, and suggests that this can happen because the professionals are not able to integrate knowledge perspectives in addition to the ones revealed by their technological apparatus (the medical gaze). The third focus is about how the increased amount of knowledge challenges the experts and their decisions. It is very difficult to identify new knowledge because it is continually created. This creates situations where experts make choices, but where patients can locate experts elsewhere who can do better. The thesis gives contributions to the area of health informatics and knowledge management. First it enables an understanding the knowledge used in treatment processes, and the challenges and problems different types of knowledge may lead to. Secondly it provides insight into aspects of lay knowledge amongst patients, and what information lay people use in order to secure their interests.

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INTRODUCTION

In the Information Society of today, it is expected that everyone “takes care of them self”, information is available and it is up to each one of us to find the information, and use it for the individuals’ advantage. The citizen of the society is today seen as a consumer. We might say that the market-economical model is to an increasing extent also applied to the health system (Lian 2003). This kind of focus implies looking further into aspects of information, knowledge, technology and medical work.

Challenging the information as a panacea

Te@mwork 2007(SHD 2005) is a strategy from the Health and Social Department in Norway which draws up the “big lines” regarding how to rationalize and increase the efficiency of the Norwegian Health System. The strategy has two main priority areas: free flow of information, and electronic interaction with new actors. I will mainly focus on the first one. A core focus within the free flow of information priority is to ‘within large organizations such as hospitals, collecting information from patient records in one place in a format that makes it easy to find, update and send further.’ (ibid: 12) The information shall then flow from anywhere to anyone within the health system. Efficiency and rationality will enable this, the strategy says. But the information flow model and the proper use of information ‘implies a particular and unrealistic understanding of health care decision making and clinical practice’ (Moser and Law 2006: 57), in that the ‘programme takes uncertainty to be a ...technical matter of insufficient information.’ (ibid) The authors claim that information in medical practices does not simply flow, but is fluid and changes its form and character in unpredictable ways. The information flow model is often represented as a panacea, and this can be compared to the illusions outlined by the reformers in the French revolution (discussed in Foucault 1973) who talks about how resources should be available for everyone, something that eventually would remove all hierarchical, feudalistic

barriers and bring 'to an end the bounded, dark kingdom of privileged knowledge and establish the unimpeded empire of the gaze.' (ibid: 39)

Anthropologists like Thomas Hylland Eriksen and social scientists like Anthony Giddens do not share this view of ubiquitous information as an obvious good. "The tyranny of the moment" (Hylland Eriksen 2001) is describing how the increasing amount of information creates a "time clamp". We spend much of our time looking for information which can help us take decisions. We use technology to "help us" with this. But in spite of time-saving technology we have less time than ever. In the same way, Giddens (1990, 1991) focus on how the production of information requires an increased use of time in order to investigate and analyze available choices. This again has implications for the conception of the self, that is, the Information Society affects the way we look at our selves, in the way that we are supposed to continually reflect on our self-identity. We are supposed to find out who we are, take care of ourselves, and find the right expert in helping us with this. Society in post or high modernity is thus as well conditioned by expert systems. These expert systems are a result of high modernity in the way that existential problems like death, sexuality, madness and illness are taken care of by experts on techniques in an instrumental and economic rational way. Existential problems are hidden from day-to-day life (Giddens 1991). The increasing number of available choices creates a situation where information is fragmented, spread amongst several actors or experts. The fragmentation of information creates fragmentation of knowledge as well. The expert, supposed to know everything supported by the increasing quality of streamlined information flow, is in fact also challenged by the difficulty to collect all relevant knowledge. The expert has knowledge of more and more specific issues. In order to obtain the knowledge in specific areas, years of training and experience is demanded. The professional doctor is a result of this. The professional doctor tends to focus on processes which can be identified and interpreted through the technological lens. In order to be a brain or neurosurgeon focus and training on specific techniques are needed. Because of the fragmentation, knowledge obtained by one surgeon may however be constantly modified by new knowledge obtained by another. The surgeon has to both know a lot, and constantly learn something new. The surgeon's interests is based on his or her knowledge on performing operations, but also on other factors like efficiency in operating as many patients as possible, and in obtaining new knowledge by attending conferences and discuss with other

experts, or by reading journals. If we return to the initial aspects regarding how the citizens are supposed to take care of themselves, find information, and use their rights as consumers, we can see that the patient-citizen, the lay people, have several interests as well. The market-economical system does not however guarantee a central controllable interest to which all other interests automatically fit. There are different interests, obtained by different actors. We may call these interests modes of reality, that is, there are different ways to see reality by each different actor. Each actor has also different interests within herself. She has to constantly take into account individual “internal” interests and weigh them up against interests claimed by external actors. These different ways of seeing the reality shapes the strategies lay people use in order to secure their interests.

Technological media in the Information Society

From the above mentioned examples; we can see that the Information Society creates important challenges for both the individual and the organizations. In the health system this affects patients, and in situations where these are children, their parents. For the patients and parents Information Technology enables an extensive reach of information through Internet. Internet is a technological medium where information previously hidden for lay people is made accessible.

Internet is an important actor in the Information Society, and brings with it new possibilities and new challenges. The increasing amount of information has for example posed challenges regarding the handling of information. The importance of handling information affects the life of the individual, how the individual lives, and how the individual uses societal resources (as Eriksen and Giddens claims). It also determines how an organization treats information. The hospital institutions have to localize important information and strive to be well equipped and well resourced in order to provide essential expert knowledge in their specific areas. The result of this is the establishment of corporate IT frameworks (like portal solutions). These portal solutions are parts of the corporate strategy, and are created and implemented in order to maintain and preserve, as well as identify and “filter”, internal information. Examples of such frameworks are the digital versions of the patient records, called electronic patient records (EPR). EPR is a ‘digital collection or compilation of registered information regarding a patient which has been in

contact with the health system' (KITH 2006). The information shall be used for securing health services, planning, leadership and research (SHD 2005:16). Each organization must have its own patient record, 'different organizations cannot use joint patient records.' (KITH 2006, my translation) The EPR is seen as a core in the teamwork strategies goals regarding flow of information (SHD 2005). Because transition from paper to digital information requires standardization, implementation of EPRs transforms the organizations as well (Atkinson and Peel 1998, Berg 1997). The history of the EPR in Norway (Ellingsen and Monteiro 2003a) demonstrates that this implementation and transformation is not an easy task, but rather a complex one where political, economical, juridical, health qualitative interests pursued by different actors, interfere with rational market-economical perspectives.

Challenging the “knowledge-as-an-object” view

Due to the increased challenge modern organizations meets in managing their corporate knowledge, the field of knowledge management was “born” in the mid-1990. The idea was and is that knowledge can be shared through sharing of information, that is, tacit knowledge can be turned into explicit knowledge through a knowledge creation spiral (Nonaka 1995). This knowledge management strand thus treat knowledge as an object separated from the subject who knows (Walsham 2005). The focus is on how knowledge can be defined, decontextualised and transferred within organizations now that Information Technology and the information infrastructures are increasingly improved for matters of communication between different parts of an organization. Knowledge is however a very complex and discussable concept, which these authors (in addition to Nonaka this regards also Davenport and Prusak 1998) to a large extent avoid to discuss. Human knowledge, how a human being knows something, has been discussed amongst philosophers, sociologists and others for many years. Tsoukas and Mylonopoulos (2004) claims that the way we look at knowledge is a 'result of the mechanization and secularization of the world during the modern age', and that knowledge as a result of this 'was extracted from social practices and contexts, taking instead the form of a manual, which contained generic statements – information – describing how the world works.'(ibid: 3) Tsoukas and Mylonopoulos continues with saying that 'the electronic storage, processing and retrieval, and the instant communication of information, manifested most impressively in the Internet, have made it so

tempting for us late moderns to view all knowledge in terms of information. This leads to information reductionism: we believe we get to know the world through layers of abstract representations about the world.’(ibid) Tsoukas and Mylonopoulos give an alternative point of view of what knowledge is, types of knowledge and especially how knowledge is used within organizations something which creates complex knowledge systems. The focus on organizations as knowledge systems enables an elaboration on ‘how organizational members` work-related experiences are turned into publicly accessible knowledge’, that is, how ‘information is elicited, interpreted and applied by organizational members in the particular circumstances confronting them, within the context of working with others; and how new usable knowledge comes about as a result of individuals applying what they know in ever-changing open-ended contexts.’ (ibid: 7) With this views in mind as a point of departure I can look into how individual actors create, use and distribute knowledge within the organizational context, and in order to perform across different individual communities (like secretaries, nurse and doctors). The knowledge systems possess both activities which can be standardized and coded into technological artefacts, and not standardized activities which is a part of the situated practice.

The complex transformation from paper to digital

The strategy from the health sector says that the health sector shall appear as an integrated service provider from the general practitioner (GP) to the “expert” hospital. ‘Interaction presupposes that the actors are well-informed about each other and has knowledge of what each of them does’ (SHD 2005:2, my translation). This implies a standardization of working practices in order to give a general indication on the different activities provided by different actors. Te@mwork further says that there is a ‘lack of coordination between verbal definitions of concepts and technical representation of the same concepts’ and further that ‘the concepts must be given a formal technical representation that the suppliers can relate to when developing their systems’ (ibid: 13). In addition to the standardization of working practices, there also has to be standardization of concepts. This regards description of diseases and sufferings as well as how to structure and write reports. But as several has noted communication and information exchange in hospital settings are very complex (Moser and Law 2006), and a streamlined and pure technological focus might sometimes be too narrow (Ellingsen and Monteiro 2003b). The medical

record is not a structured document, but rather a complex framework with multiple “realities” (Berg and Bowker 1997). The technical view has a tendency to define information as knowledge and ignore the complexity of working routines, norms and regulations which is difficult to describe semantically, something Brown and Duguid (1991) call actual practice in difference to espoused practice.

My intention is to identify the actors and communities (like secretaries, doctors and nurses) who collaborate to perform the patient treatment process. The treatment¹ process is the patients “way” from when the disease is identified, until the case is closed, but I will mainly look into what happens inside a specific department at Rikshospitalet. The treatment process implies cross-community collaboration between different knowledge systems like doctors, nurses, administration personnel often communicated through or within technology. To have an understanding of these knowledge systems implications and motivation, also historically, is then an important factor in understanding how these systems interact in relation to the patient treatment process.

The introduction of the “knowledgeable patient” into the medical network

Brian Wynne (1996) elaborates on the concepts of scientific and lay knowledge. In relation to the Chernobyl catastrophe the sheep farmers in Cumbria, North England had to prevent their sheep from grazing for some time because of the spillage of radioactive decay. Wynne describes how the farmers’ local knowledge was valuable to identify local factors which the scientific expert community on pollution did not focus on. This relates to for example how the different type of local soil (mountain, mud, stone) affected the amount of time needed for the pollution to disappear. The scientific community used a quantifiable universal and general rule for deciding how long the sheep had to desist from grazing. From this story Wynne discusses the concept of scientific and lay knowledge. The dichotomy scientific and lay are maybe a bit theoretical, but nevertheless valid. It could however be helpful to further identify different ways of describing the aspect of patient knowledge and participation in the “modern society”. We can see from Wynnes

¹ A doctor will often focus on the treatment process as consisting of diagnostic first, and then the treatment. For matters of simpleness, I use the concept treatment. I am interested in the totality of the process

story that the lay knowledge is an important resource. Wiener et al (1980) focuses on how the patient power movement is 'part of the general consumer movement', which brings with it expectations of return of money outlay and legal rights and is thus 'a reflection of the whole movement of increasing client participation in services' (ibid: 31). The modern patient can then be seen as a consumer (AHRQ 2006), and customer rights in health services are seen as equal to those in rest of the society. On the other side of the scale we have those who focus on the patients as a victim of an increasingly complex society where risk creates sickness (some perspectives summarized by Førde 1996). Hjortdal (2002) elaborates on these extremes by introducing four concepts to describe the 'modern' patient: the patient who is in coma, the old-fashioned or tolerating patient, the consumer patient and the informed and involved patient. Hjortdal then claims that the patient can be consumer focused, or passive and receiving but in addition there is a new type of patients which is engaged in making decisions. 'These patients can easily challenge the doctor's knowledge base and patience' (ibid). The introduction of patient power (Wiener et al 1980) and Internet technology enables new configurations of the medical network (Hafstad 1999)

To see the different knowledge communities, like doctors, secretaries, nurses on one hand, and the patients or lay people on the other, and how they intertwine, combine and collaborate performing treatment, is an important element in understanding their interrelationship and compatibility, but also when and why incompatibility sometimes occur. My three research questions are then:

First: Who are the main human actors engaged in the patient trajectory, what is their knowledge in relation to the treatment process, and how is this knowledge accomplished, used and distributed during the trajectory, **secondly** how is Information Technology used in this knowledge creation, application and distribution and **thirdly** how do the patients or parents behave in the interaction with the doctor in order to secure their interests?

An interpretive approach where I seek descriptions of people's interpretations of the way they see the world, can help me identify interesting points which can help in the continual improvement of the health informatics area.

I believe that this study describes how knowledge actually is used and distributed by different important communities within the hospital. It rejects the assumption that knowledge is the same as information, and can hence be explicated and written down by each one of the actors. It also describes how different actors creates networks across communities in order to perform the patient treatment, and finally it shows that patients and parents interests, based on their local knowledge about their own situation, have to be taken into account in order to make a successful treatment process.

The focus on the doctor – patient/parents interaction can help identifying important issues which can be issued in appropriating Internet for patient use in contemporary society. The Information Society provides overwhelming quantities of information, and an approach based on sound mediation between medical and more “popular” information could be of importance in meeting the new era in an active way.

Target audience

This thesis is about how different human actors use technology when their practices are performed, and about how professional workers like secretaries, doctors and nurses interact with lay people like parents and patients, in performing a treatment process. It is a Master Thesis, written in a particular profession: medical informatics, information systems, human and technology, and knowledge management. It is thus written for researchers and academia. These can see the thesis as a discussion of the issues of scientific and lay knowledge, how contemporary society conditions these knowledges, and how a process like the treatment of sick patients, is affected by this situation. On the other hand the thesis implies describing professional practitioner’s knowledge work, and lay people like parents and patients participation in the treatment process. I think therefore that the thesis could be interesting to read for these as well, as it has certain findings which may enable an improved understanding of communication between experts and lay people.

Motivation and expected contribution

When I started my master thesis at Rikshospitalet, I was already interested in the concept of knowledge and knowledge management in organizations. I was first involved in an out patient clinic meeting between patients, parents and doctors. My initial aim was to see how professionals used the CSAM²-portal. I noticed a, for me, interesting phenomenon: the parents were actively participating in the decision making. That is, they were able to both discuss with the doctor, and correct him when they felt it was needed. This observation made me focus on knowledge, how the parents' knowledge about the specific child is an important factor in the medical discourse, and how it stands in relation to the physician's scientific knowledge. This creates a situation where different knowledges have to be taken into account. They have to be understood when decisions are taken. My aim was thus to look into these knowledges, and how they were used when performing treatment. The expected contribution regards looking into the interests of the professional workers and the patients, and how these are taken into account when decisions are taken. This presupposes an understanding of aspects within the different knowledges. The contribution may create an understanding of the different logics or interests which forms the knowledges of the professional workers on hand and the lay people on the other

The structure of the thesis

The rest of the thesis is organised as follows. In Chapter 2 I first relate my work to research done in several different fields regarding knowledge perspectives and practices, before elements of the classic version of the theoretical framework of Actor-Network Theory (ANT) are mixed with elements from the more recent version. Classic and late ANT is mixed in order to grasp the occurrences of multiple interests and several modes of ordering in the interaction between health professionals and lay people. Chapter 3 contains the research approach. First a brief description of the setting is given, before I describe research methods applied in fieldwork. Chapter 4 is the empirical chapter and contains the case of knowledge workers creation, use and distribution of knowledge. Within these knowledge communities' practices Information Technology is an important medium. The chapter ends with four vignettes which demonstrate how patients and parents together with the doctor enact on the treatment process. The analysis chapter the

² Clinical systems all managed (CSAM) is an ambitious framework which includes architecture for security and integration as well as a methodology, a program for benefits realisation, and a concept for administration

knowledge communities' work is briefly discussed, before the process of enrolling patients (or doctors) is described. To the background of the aspects found in the translation process, three issues are further discussed. These issues regard how professional and lay knowledge is mixed or not mixed when decisions are made in the treatment process. In the discussion I tend to draw generalizations from my thesis, and discuss them briefly. The chapter ends with possible further work, and concluding remarks

THEORY

2.1 Introduction

This thesis addresses how different types of knowledges are used in order to perform treatment processes. The phenomena I will investigate are first how professionals set up a treatment process and attach resources to it, and secondly how professionals and lay people interact in order to optimize the process. The investigation contributes to identify knowledge elements which together with a relational framework enables an understanding of what happens when the interaction ends in conflict and when it culminates in successful treatment.

In order to get an understanding of the different actors' activities, and their knowledge on how to perform these activities, I will first identify different knowledge perspectives or elements. The first part thus implies a definition of epistemological fundamentals, knowledge perspectives, organisational knowledge and knowledge in practice. The individual knowledge is shared through collective performance in practice within organizations. The communities of practice enable, in addition, a perspective which gives an understanding that there are different knowledge communities within organizations. Professionals like nurses, secretaries and doctors all have their different focuses, and interests which is discussed, emphasized, increased and negotiated within these communities. The professional knowledge of hospital workers is different from the knowledge lay people possess. The professionals at the hospital have to focus on organizational issues like creating pre-defined categories into which individual patients are positioned. They have to treat as many as possible. Lay people on the other hand have more "personal" and individual focuses which relates to several issues regarding their personal situation. This will be discussed in section 2.2.5.

Secondly a relational framework will be introduced. The knowledge elements have important aspects but needs to be related. Actor-Network Theory (ANT) outlines a relational and

procedural framework where different actors enact in a process. In addition ANT gives a rich vocabulary from where suitable expressions and descriptions may be picked. A third important ability ANT has is the common symmetry for descriptions of human and non-humans. ANT then enables a description of different actors, both humans and non humans like technology, as working together performing action. The action consists of performing expertise in different parts, and on different points of time, in the process. The expertise, or knowledge, is performed by the use of different types of actors like telephones, different information systems, pen, paper, post-it notes, discussions, negotiations, operation equipment etc. Actor-network Theory thus gives us the ability to look at action as networks of relations between several actors. A main aspect of late ANT is however how different realities, modes of ordering, in short interests, are translated when establishing networks. By using the relational aspect where actors meet across communities creating networks which performs action, describe the process through a four step translation process, and adding the aspects of multiplicity and interference, classic and new ANT is used together.

2.2 Review and positioning

2.2.1 Knowledge perspectives

In this section I will first identify different types or perspectives of knowledge. The point is to identify types of knowledges or perspectives which can be used to grasp both scientists and other professionals' knowledge, and lay knowledge regarding individual aspects.

To define knowledge is very difficult if not impossible, and there are different views on the concept of knowledge. The study of knowledge is often called epistemology. According to Crotty (1998) there are three basic epistemological fundamentals: objectivism, constructionism and subjectivism. *Objectivism* focus on how things exist as meaningful things in themselves, independently of consciousness and experience. By using a proper lens, like a mathematical algorithm, universal knowledge can be obtained. *Constructionism* rejects this view and says that 'truth or meaning comes into existence in and out of our engagement with the realities of the world; there is no meaning without mind. Meaning is constructed not discovered.' (ibid: 8-9) In the third stance, *subjectivism*, meaning is seen as coming out of a situation where the subject gives the object meaning. (ibid) We can see these three different aspects in the relation to an

object. In objectivism the object has been there all the time waiting for someone to discover its objective meaning. In constructionism the object and the subject are interrelated partners which construct meaning. Subjectivism focus on how the subject gives meaning to the object, and the object has no stake in this. A pen is a pen if we choose to see it that way. The pen in itself gives us no constraints as subjects.

In my thesis I have the need for a knowledge concept which relates to both the professionals and the lay people, and Blackler (1995) identifies five knowledge types, which can be used for this purpose, namely knowledge as embrained, embodied, encultured, embedded and encoded. *Embrained* knowledge is according to Blackler the ability of abstract thinking and can be the knowledge of theorists like Argyris and Schön. We can call it the ability to understand complex causations. *Embodied* knowledge is rooted in specific contexts and is acquired to sentient and sensory, face-to-face discussions, and acquired by doing. This is then a very “tacit” form of knowledge, which is only partly possible to make explicit. The *encultured* knowledge describes how working environments in organizations holds different kinds of cultures which are specific for them, hence the process of sharing understandings. This also relates to the concept of communities of practice (more on this issue later). The *embedded* knowledge is about how rules and regulations are “inscribed” into the formal procedures, and finally the *encoded* knowledge which can be codified and transferred (earlier in books and manuals, now as electronic information). In organizations all these types of knowledges exists, but they are used to a varying degree. This relates to the focus of the organization, that is, what type of configuration it has. The professional bureaucracy³ emphasis is often seen as being (according to Blackler) on the embodied knowledge (ibid: 1030). This means that the professionals who are the key persons at the hospital to a large extent have to rely on their embodied knowledge. Embodied knowledge can be objectivistic, subjective or situated within the epistemological fundament of constructionism. Examples of this will be given later.

We have so far identified different types of knowledges, and placed a particular type of knowledge to the configuration of the hospital as a professional bureaucracy. Further on I will

³ The professional bureaucracy (Mintzberg 1983) is institutions like universities, hospitals, etc where the key part of the organization is the operating core (the teachers, doctors etc) and where these have some amount of freedom in their job performance

discuss on the subject of organizations and knowledge

2.2.2 Organizational knowledge and knowing in practice

In this section I will relate the perspective of embodied knowledge to the organizational practices. This enables a bridging between individual knowledge and how it is used in performing organizational activities.

The embodied knowledge competencies of the key members in the hospital are exchanged through encounters, discussions and practice and the organization is then a place, a location, where a set of dynamic social interactions (both internally and with the outside world), enables individuals to develop and refine their knowledge sets and skills. Aided by organizational information systems, the organizational knowledge is thus used by members who have learned to 'make judgments within a collective domain of action, based on an appreciation of context and/or set of generalizations' (Tsoukas and Mylonopoulos 2004: 8). From this we can see that knowledge is performed in practice, collectively, and that individuals learn from the constant interaction with one another in performing practice. We also see that knowledge is contextual, related to the specific local situation where it is used, and that it can also be theoretical. Because knowledge is practical or theoretical, collective and situated, organizations can be seen as knowledge systems. Tsoukas and Mylonopoulos say that this view of organizations as knowledge systems implies a concern with at least three issues: (a) how individuals exercise their judgments and create new knowledge in the course of their work and/or of interaction with other people; (b) how collective domains of action are sustained and particular values and beliefs within them become institutionalized; and (c) how particular sets of generalizations, abstract categories...and abstract statements of the if-then type are selected, institutionalized and modified (ibid:8-9). Viewing organizations in this way 'highlights the crucial role of human interpretation, communication, and skills in generating effective organizational action. It also underlines the dynamic character of such processes since they unfold in time, in context of social interaction' (ibid: 13)

'A knowledge based view of the firm enables us to move beyond the individual to explore the broader social basis – the social practices, forms of interaction, routines and the work

organization – upon which individual knowledge and action draw’ (Tsoukas and Mylonopoulos 2004: 13). This enables an understanding of knowledge as something people do performing practice (Blackler 1995). This can be related to the view outlined by several situated practice researchers (like Suchman 2000, Orr 1996), but also the view of knowing as an enactment outlined by Gherardi and Nicolini (2000) and discussed by Law (2000). They look at knowledge as an enactment, not an objective decontextualised thing separated from the things we do. As Moser and Law (2006) emphasizes as well: knowledge is created out of materially heterogeneous equipment and is thus conditioned by an enormous complexity. Moser and Law are also very critical towards the view of information as a stable essence which flows seamlessly between different devices, and they propose a view of information as fluid. The situated practice is based on the ability to know-what-to-do in specific situations, rather than managing structured, rational and foresightable information or activities in a stable manner. The knowledge is often actually distributed to different objects like technology, images, written letters, other subjects etc. Each subject and object holds different parts of information (and thus knowledge in the specific situation), and knowledge is called upon integrating subjects and objects in action.

We could say that the organizational collective system(s), enables a possibility for knowledge creation, in that novices can learn from learned workers, but also that they can bring with them new perspectives from the “outside”. It enables distribution, in that knowledge can be collectively “spread” from one knower to another (in practice or discussions); and use, in that the knowledge gained is used in the daily work. But the process of creation, use and distribution is basically performed within communities which share the same interests and practice. This could be nurses, secretaries or physicians at hospitals. They all have their own community within which knowledge is used and spread. This is often called communities of practice. The different communities of practice have however their own knowledge perspectives (in relation to Blacklers definitions). The doctors and nurses are professionals who have an inherent embodied knowledge gained through education and practice. The secretaries have another type of perspective, which to a larger extent relates to the embedded knowledge types where routines, norms and regulations have an important implication. Their abilities is to a larger extent defined and structured in routines, although much of it is tacit as well (as we shall see)

2.2.3 Communities of practice

The professionals belong to different communities of practice, which is the same as working groups whose practices differ. These communities increase their learning when the boundaries are stretched as a result of tension between existing competency and new experience. This type of process is also important for learning between communities. These communities of practice are in possession of some sort of expert knowledge obtained through ongoing interaction with “expert environments”. Professionals are consisting of different groups with different perspectives, but these groups hold similarities when it comes to structures and content. The doctors have their community and focuses, while the nurses may have different cultural aspects. At an abstract level the hospital can be seen as a community, but I find it more appropriate to describe nurses, doctors and secretaries as communities and the communities together as knowledge systems.

What are Cop's?

Communities of practice (CoP) are groups of people who are ‘informally bound together by shared expertise and passion for a joint enterprise’ (Wenger and Snyder 2000:139). This could be groups of physicians, nurses or secretaries who communicate within their own communities, between individuals, in order to perform their practice. This means that CoP has three basic perspectives (Wenger 2000): mutual engagement (the domain) in that active participation in practical tasks develops roles, relations and identities; joint enterprise (the community), where goals are realised or accomplished through common engagement; and shared repertoire (the practice) which enables development of common routines, word, tools, symbols and histories, and that these constitutes a common resource when opinions are formed. CoPs are thus not only casual teams but individuals who together create collectives with common interests. The difference between CoPs and mere teams can be described by four “attributes”: They (CoPs) solve problems quickly, they transfer best practices, they develop professional skills, they help companies recruit and retain talent. CoPs differs then from “ordinary” teams, in the way that activities in relation to the production of a service, focus on ‘developing members capabilities; building and exchanging knowledge, and that they are informal self-organizing communities who set their own agendas and establish their own leadership’. (Wenger and Snyder 2000:142)

Boundaries

Wenger (2000) focus on two important aspects in relation two learning in organizations. He talks about competence and experience. Competence is about what it takes to be a member of a CoP. That is, you have to qualify. The second aspect is the ongoing experience of the members. Wenger says that these two can sometimes stand in opposition to each other, but that it is 'whenever the two are in close tension and either starts pulling the other, learning takes place' (ibid:227). Learning is then some sort of interplay 'between social competence and personal experience. It is a dynamic, two way relationship between people and the social learning systems in which they participate. It combines personal transformation with the evolution of social structures' (ibid). The concept of boundaries can also be used to understand learning between different communities. Because one has to learn, obtain some new sort of knowledge, learning can sometimes be "hampered" if there is too little divergence within or between communities. 'If competence and experience are too close, if they always match, not much learning is likely to take place. There are no challenges; the community is losing its dynamism and the practice is in danger of becoming stale. On the other hand, if experience and competence are too disconnected, if the distance is too great, not much learning is likely to take place either' (ibid 233). Boundaries can then be a good place for learning for individuals and communities because they imply close tension between experience and competence. (ibid)

Organizations, then, consists of communities, which have their own domain, culture and practice; which learn when competence and experience meets at the borders of the communities; and which cultivate the social learning systems, enabling the individual to focus on her own role in the community. Tsoukas and Vladimirou (2001) say that 'through experience and participation in a community of practice, operators develop a set of diagnostic skills which over time become instrumentalized, that is to say, tacit. This enables them to think quickly, 'on their feet', and serve customers rapidly. Over time operators (workers) learn to dwell in these skills, feel them as extensions of their own body and thus gradually become subsidiary aware of them, which enables operators to focus on the task at hand' (ibid: 987). I will return to a description of communities at the hospital in sub section 2.2.7

2.2.4 The concepts of scientific and lay knowledge

There are fundamental differences in the knowledge of professionals and lay people. Although both have embodied knowledge difficult to make explicit, the differences relates to the different roles they have. Experts have to treat a large amount of specific situations, while patients are receiver of this service. The knowledge of the experts is based on the ability to place different individuals in pre-determined categories in order to treat as many as possible. The knowledge of lay people is based on knowledge about local and personal factors.

The implications of the concepts of scientific and lay knowledge might have increased in the age of modernity. Giddens (1990) claims that modernity, and technology increases the complexity in our society. He argues that knowledge about the social world and social activity is reflexive, it changes all the time, resulting in knowledge in a specific area, is not known before-hand. This creates less control because of four factors:

Differential power: Some individuals or groups are more readily able to appropriate specialised knowledge than others

The role of values: Values and empirical knowledge are connected in a network of mutual influence

Unintended consequences: Knowledge about social life transcends the intentions of those who apply it to transformative ends. The reflexivity of modern social life blocks off the possibility to control the number of alternatives (choices)

The circulating of social knowledge in the double hermeneutic: Knowledge reflexivity applied to the conditions of system reproduction intrinsically alters the circumstances to which it originally referred (44-45, 54)

The amount of knowledge in the world is increasing, and this radically increases the number of possible solutions. This again means that knowledge is continually modified (because new

knowledge is created), and a strange effect arises, in that the knowledge which initiated a process is modified and thus alters the circumstances, for example the motives, behind starting the process. We can thus imagine that expert groups are created, and that these expert groups, for example scientists, physicians or others, have access to information “ordinary people” hardly can ever obtain. Giddens point however is also about how the special expert knowledge rapidly increases and changes, and how this “troubles” the updating of knowledge and that the new knowledge changes the relevance of the problem the knowledge initially tried to solve. In medical situations we can see this in the way that diseases, treatments and techniques are continually modified by new knowledge. This makes it difficult for the clinicians to update themselves on “new” knowledge, and the knowledge may also reject old knowledge like techniques and treatment. It is then very difficult for each hospital environment to be updated in the continual creation of information.

Wynne (1996), on the other hand, addresses an increased focus on the nature of what Giddens sees as insecurity and apathy amongst lay-peoples relationship with what Giddens call expert systems. In his article he basically has two messages. He first says that modern biotechnology and information revolutions are alienating and impenetrable for the layman, and that this creates some sort of a defence mechanism. Wynne describes how the overwhelming power of expert system creates apathy amongst the lay people, and that this type of alienation often is mistaken for unambiguous trust (ibid: 53-55). Secondly Wynne continues with saying that lay knowledge contains at least two factors not given by the reductionist view: people give socially valued dimensions to their view; and the lay conception of risk, and hence the understanding of the possibility of occurring accidents, are richer than the controlling body imposed by experts upon lay people demonstrate. This controlling body is a powerful, but rescuing, tool placed upon lay-people to save them from disasters when these happens, but Wynne claims that ‘the vernacular, informal knowledge which lay people may well have about the validity of expert assumptions, about real-world conditions, about the production, use or maintenance of a technology, is also an important general category of lay knowledge that is usually systematically under-recognized’. (ibid: 59). The expert systems are seen by the lay people, according to Wynne, as dense but inadequate, as a ‘taken-for-granted culture of prediction and control.’ (ibid: 67). The difference between lay people and scientists are thus that while lay people admits lack of control over

“many environmental and surrounding social factors”, the scientific culture preaches control, and sees the layman as irrational and ignorant (it may be noted that also lay people tend to see the opposing expert person as ignorant). The layman has thus the tendency to react with ambivalence towards experts who engender alienation and social control. The fundamental risk for lay people argues Wynne, is risk to ‘identity engendered by dependency upon expert systems which typically operate with such unreflexive blindness to their own culturally problematic and inadequate models of the human’ (ibid: 68). The nature of the knowledge types then, Wynne continues, is that the scientific knowledge is non-neutral and ‘correspond with particular cultural and epistemic principles – instrumentalism, control and alienation’, while lay knowledge is ‘not some romantic state of lack of control, but rather a control seeking mechanism based on knowledge manifested in local contextualism rather than decontextualised universalism’ (ibid:70)

Giddens emphasizes the rapid rise of parameters, variables and choices. The increasing number of alternatives makes it harder to be updated for the expert, harder to choose for the lay people, but it makes also earlier choices invalid because the original problem they were supposed to solve has been altered as a result of new knowledge. Wynne argues that the expert scientists ignore the contextual focus; they do not take into account the environmental and social contexts. This creates a divergence between the experts and the lay people where experts regard lay people as trivial, ignorant and irrational, and were lay people sees the expert as ignorant and “theoretical” not able to understand the “real life and work”. However, both knowledge types have valuable contributions. The scientific knowledge learned and used by experts reduces the complexity of social systems by introducing a number of suppositions in order to handle tractable problems (Lopes Cerezo and Gonzales Garcia 1996). But experts have not fully control either, even if they tend to pretend this. ‘Expert knowledge is not epistemically self-sufficient: it is constrained by but not dictated by nature’ (ibid: 5). The lay knowledge is held by ‘all those people who have some knowledge in virtue of their direct involvement or their personal interests (political or otherwise) concerning the problem at stake (e.g., agricultural regulations, waste disposal, energy consumption, fishing policy) and do not hold relevant scientific credentials’ (ibid: 3). It also have some negative and positive attributes. The negative is that the complexity and some times uncategorized structure (or non-structure) of social systems tends to be difficult to use across different contexts. It is for example important to reuse “good patterns” for dealing with disease

and epidemics, and these patterns are obtained through finding a common measurement standard that can be used across disciplines. The lay knowledge has, however, also important advantages. Phenomenon of nature and society is often highly unpredictable and deeply contextualised, that is, they occur at specific local settings because of local factors. In this matter the local knowledge (often provided by lay people) may 'provide useful information concerning known parameters and their relative significance for the social system's equilibrium... the local knowledge can also point out new perspectives in the sense of showing the relevance of dimensions (e.g., culture and traditions, local economic practice) that have so far been omitted from expert knowledge claims.' (ibid: 7) In addition to the importance of mixing scientific and lay knowledge in order to obtain both generalizable and specific solutions to problems, it is also important in order to maintain political stability and avoid social resistance from lay people who act and protest against overwhelming use of political power. Including lay knowledge in public decisions is hence a factor in maintaining social stability.

In summary we can conclude that Giddens identifies various problematic issues that characterize contemporary society. The experts systems have expertise in areas where knowledge is continually modified, revised and changed. Lay people understand this, and the former trust towards the expert is not longer automatically guaranteed. Wynne on the other hand says that lay people are experts on local conditions, and that they see the rational knowledge of scientists as ignorant and unreflexive. Cerezo and Gonzales Garcia says that the expert knowledge is constrained but not dictated by nature, and that the unpredictability of nature related to local factors can sometimes be better understood by local actors. The professional knowledge of the doctor or nurse thus differs from the local knowledge of patients and parents. Even if this knowledge has incompatibilities, it can also be used together in order to create successful treatment processes (this is further analyzed in the analysis chapter).

I will now turn to how knowledge relates to technology, that is, how Information Technology and information systems can be, and is, used in relation to knowledge work.

2.2.5 Knowledge and IS

As Walsham et al (1988) claims 'information systems in organizations are not just technical but should rather be conceptualised as social systems in which technology is only one of the dimensions' and 'social systems because they concern interplay of human, organizational and technical factors which cannot be easily separated.'(Walsham, Waema and Symons 1988) An information system is thus not only technical systems, but also the social factors around a working process. Technical Information systems can be used as a facilitator and a medium to create efficiency, but it is important to carefully define how it shall be used in order to maintain the strengths of the professional bureaucracy.

The view of organizations as knowledge systems, built and developed through situated practice (based on competency and experience) where much of the knowledge is tacitly embodied and difficult to explicate and separate from the specific situations, implies a critique of the knowledge management strand. This strand treats knowledge as decontextualised objects which are universally applicable, and separated from the subject who knows. Within the IS literature there are several studies which are well aligned with this critique. Thompson and Walsham (2004) describe a case study where an IT organization tried to import a practice where subjects had to register their knowledge in repositories (in order to make it explicit). The project included three types of KM initiatives: collecting data, codifying information and generating meaning. The first project was not successful as the subjects did not see the point in registering their "knowledge" in repositories. This was 'information which they would have been happy enough to have provided through communicative interaction' (ibid: 731). Regarding the second the authors found that in situations where technology was tailored to specific groups, initiatives were successful, but that these tailored products could hardly be used outside its context. A problem related to this second point was the inability or impossibility to write up "in-between lines" information obtained in interaction with clients (ibid: 732). The third was seen as the most successful as it implied some sort of continual inter-subjective communication between individuals (ibid: 733). This KM initiative was basically based on corporate yellow pages, informal interaction, interest groups and e-mail. As it "cultivated" the face-to-face interaction (instead of trying to replace it) it was more aligned with the way the consultants worked and consequently more successful. This was successful, because the knowledge was not separated from the context. The authors conclude by saying that the 'importance of contextual analysis is necessary if organizations are to avoid the

mistakes of the past and ensure better targeting of their investments in methodologies, best practice, application software, special interest groups, and other forms of support for shared organizational endeavour.’ (ibid 743) Other IS literature criticizing the knowledge-as-decontextualised-object literature is Walsham 2001, 2005), Walsham and Barrett (2005), and McDermott (1999), while Brown and Duguid (1998) also touch technological aspects of knowledge management. All of them emphasize the importance of understanding knowledge as something related to the context where people know and learn through interaction. This means that cultivating processes is a sounder strategy than pursuing objects (or ‘knowledge’) to be registered in repositories (Thompson and Walsham 2004). Human thought is often tacitly embodied and in order to design Information Systems for knowledge management (like the EPR), the members of different communities must participate in the development. The system must provide information while the organization at the same time upon this layer of information, enables and cultivates interaction. This also means that Information Technology is seen as a possible provider of information which can stimulate participation and simplify things for the different communities. Walsham (2001) outlines possible improvements in KM strategies being facilitating communication done by individuals in CoPs; appropriate reward systems; and the creation of safe enclaves (ibid, see also Berg and Goorman 1999). These authors thus identify themselves within the area knowledge-as-practice, as they see ‘knowing-in-practice as an individual process, inseparable from practical action, with knowledge communities as key learning areas, and taking place in contexts where power relations matter’ (Walsham and Barrett 2005:7).

We can see that there is a struggle between how much it is possible to encode in repositories, and how that should be encoded. As we have seen the problem is to find the balance between encoding and facilitating. While organizational information systems (like EPRs) are established in order to define, collect, and share information which is relevant for the organization, thus can be seen as organizational knowledge management systems, the lay people have to a limited degree this “luxury”. The information engine for the lay people is basically the Internet, and I will briefly introduce some aspects related to this.

Internet and lay knowledge

Internet is seen as a possible challenger to traditional role configurations, and is an extensive “library” where lay people can access information. I will thus briefly touch upon issues relating to implications of Internet use amongst lay people.

The Information Society and the modern life, with Internet and additional information resources, as well as an increased focus on consuming, challenges the traditional role configuration within the health system (Hafstad 1999, Hardey 1999, Hjortdahl, Nylenna and Aasland 1999, Coultier 1999) as the Internet enables a “sharing of power” between key actors like physicians and self-management groups (Dickerson and Brennan 2002:198). It also has enabled new patient roles (Bellika and Larsen 2001). Internet is however not a structured tool where information is controlled and portioned, and as Hannemyhr (2005) claims, there are many problematic aspects connected to it. Dickerson and Brennan (2002) identify three common ideologies regarding the ability of Internet as a power structure in patient-provider relations. Let us call them the conservative, the positive and the capitalistic elements. The conservative is about how Internet information creates excessive burdens on the health profession as the doctor then has to help the patients to search for “good” information. The second is about how technology is seen as a good which will improve life. The third regards the superiority of the market structures and how market forces improve quality and reduce cost. The authors claim that Internet has the ability to shift the power between provider and patient, and identifies two ideologies which support reform. First the egalitarian which focus on giving broad access to information and enable Internet access from public facilities. As a result of the knowledge enhancement obtained by this point, the lay people can participate more actively. The health resources then have to be effectively allocated in order to serve the empowered patient. We can thus see that Internet has important implications as well as challenges for the health profession. Internet is both a part of Information Society as well as a medium which itself creates more information. The consumer society with privatization of health institutions, and these institutions needs to market their services through media, makes information available also for the layman. Internet thus enables lay people to access information formerly regarded as “secret” and hidden from them. In these matters the Internet is an important medium, but it raises some problematic issues as well, as Dickerson and Brennan notes.

Till now I have described knowledge in hospitals as to a large extent embodied. It is obtained, used and distributed through negotiations, discussions and cooperation in practice. The practice is performed within and between communities of practice. The difference between professionals and lay people is that professionals have to categorize across unique individuals, while lay people mainly focus on their local situation. Information systems in organizations are historically attached to practice as an integrated mechanism or medium within the performances of the professionals. Further I talked about how Information Technology sometimes is seen as a competent provider of universal knowledge, and how this, through so-called Knowledge Management initiatives, may threaten key mechanisms within the professional bureaucracy in bringing with it desires of detaching the knowledge from the knower. In the Information Society there is however a need to filter and structure information according to organizational needs. By aligning Information Technology flexibly with existing practices using it as a mediator between communicative and collective action, it can serve as a facilitator rather than a substitute, and as a “friend” rather than an enemy. Although Internet has many positive aspects, the patients have to filter the information themselves. The need of patient information systems for lay people is thus obvious. Internet is however a medium where information formerly seen as secret can be accessed by lay people, this is a part of the consumer society.

2.2.6 Institutional structures and knowledge work in hospital communities

In this section my aim is to indicate that the hospital has some institutional structures that constraints the availability for the outside world. The structure thus holds some disciplinary power. Further some aspects of the knowledge communities of doctors, nurses and secretaries are discussed.

The expert hospital is organized according to certain institutional factors. From when parents or others discover that their child suffers, detected by strange behaviour or strange appearance, to when the problem is defined, framed and to some extent controlled, the parents and the patients have to go through several bureaucratic passage-points. This structured bureaucratic way is how the Norwegian Health System is organized; the system decides where, when and how a patient should be treated. This system consists of several actors from big national initiatives to the local

based institution. Examples are the government, the health sectors, the expert hospitals, county hospitals, and general practitioners etc. These again are affected by market structures, economy, culture, politics, science etc. In my thesis the focus is generally the patient treatment from general practitioner, via local hospital to the expert hospital, and more specifically what happens inside the expert hospital. From the structure of the patient trajectory, which consists of the happenings from the mother or others discovering something strange, talks to the general practitioner, further with local hospital which transfers them to the expert hospital, we can see that there are obligatory passage points the patient has to go through. Basically the system says: this is what you have to do in order to be treated. The different actors have to go through several passage points to be able to continue in the system: “you could try other solutions, but if you use our offer you have to follow our rules”. It is, however, important for this system to satisfy the patients in order to make them act as wished inside the hospital. Just think of how important it is for us when we get sick or suffers from something that must be treated by domain-experts, to have a safe and good journey, where we trust what the human actors say and do, where we can be informed, and enlightened with information, advices and medication if necessary. In short, it is important for us to trust, to be informed and to have a process with as little physical and psychical pressure as possible. These demands are sometimes, but not always, covered by the system. Sometimes the process is very slow, painful; one is thrown between bureaucratic points. This is unsatisfying for the patients. On other occasions everything goes smoothly. The process before getting into the expert hospital may or may not be problematic, but it is when the patient is transferred to the expert hospital the “real” treatment starts. National institutions like expert hospitals, and the way towards them (GP-local hospital-expert hospital), is then structured and standardized in a certain way. The expert hospitals (the clinic) exists in our society because of the increasing number of epidemics and diseases in the late 18th and early 19th century and because of the inventions of new technology and techniques that enabled the surgeons to look inside the human body and hence created modern medicine based on a combination of biology, physics, chemistry and technology (like the x-ray. This new knowledge had to be developed, used and transferred within a decontextualised environment. The basic vision was that a proper organization of health system could remove diseases (Foucault 1973, Hofmann 1993). The clinic thus created a type of epistemic culture, and this type of epistemic cultures was structured in order to remove diseases. This special knowledge or episteme was and is a requested service; it is something “special”. The

use of these resources has to be structured and organized, the patient as well as the system, has to be disciplined in order to get the service. This type of discipline, and the power which follows, is “inscribed” into the institutional routines (Foucault 1977).

The scientific doctor

The transition from bedside patient to the clinic did also lead to another important change. The nosology of the 17th century was replaced by a new type of perspective. The nosology's holistic view of the patient as a subject of the disease was replaced by a view of the disease as an object which had found an appropriate body. The nosology was about relieving, while the new medicine was about healing. In order to heal, the illness had to be identified. In order to identify, an apparatus which enabled entrance into the body had to be made, and a proper semantic for describing what was seen was constructed. The medical technology which was made consisted of using contributions from physics and chemistry obtaining knowledge about microbiology which again created knowledge about bacterial diseases. The discovery of x-rays, done by William Röntgen gave the possibility for depicted diagnostics which revolutionized the medical understanding of the body's organs and processes (Hoffman 1993, my translation). The new gaze was sensitive to difference, simultaneity and succession, and frequency, the symptom became a sign...for a doctor whose skills would be carried 'to the highest degree of perfection, all symptoms would become signs'; all pathological manifestations would speak a clear, ordered language' (Foucault 1973: 94-95). The birth of the clinic and the scientific doctor brought with it a belief firm as a rock that disease could be removed, the medical gaze saw the symptoms; there was no need for transformation or interpretation: 'the medical concepts and terms were directly observable' (Hofmann 1993.3576 my translation).

Hofmann (2001) also talks about expert systems and experts, in relation to the clinic. With the scientific revolution and the creation of more and more complex technology, the view of disease has changed from being something spiritual, to something bio-chemical, and now 'the basic phenomena and entities applied to define many central diseases are provided by technology' (ibid:11). The medical concept of disease, hence the medical knowledge of disease, is influenced by technology in two ways: 'technology is developed to detect symptoms'; 'the subjective experience of the patient is projected onto paraclinical signs and tests.' (ibid: 12) Technology not

only determines what we see and how we see it, but also the way we describe and think about our internal organs. In addition has the objectivity and reliability of the use of technology in the making of diagnosis, ‘reduced the epistemological importance of the individual person for the concept of disease; it has reduced the importance of the subjective experience of the patient’. This means that the ‘capacities of technological medicine have replaced the individual patient as the epistemological basis of the disease concept.’ (ibid: 14, Jewson 1976) We can then say that medical technology creates what the physician, the technician or the researcher see, and they see what they are looking for: *disease*: ‘The technology mediates between the seer and the seen and what is seen becomes largely constituted by technology. This is why practices change with the development of new technologies.’ (Hoffman 2001: 15) Hofmann indicates that the technological concept of the disease in contemporary society is very much based on the scientific paradigm.

We could say that the doctor’s scientific knowledge is partly encoded as well as embodied. The apparatus the doctor use is appropriated gradually by the detection of new diseases. The doctor’s work is the based on dynamic reflexive interaction with human and technological actors. This is what Ellingsen and Monteiro (2003c) call enacting, orchestrating and organization of the knowledge work. This “triad” implies a deeply moulded and internalized type of knowledge work which does not consist of parts easily separated. To manage this knowledge is to continually re-represent old knowledge into new knowledge, bringing together many forms of knowledge and look at it from different angles; and to coordinate the different task to different workers ‘across time and space and professional groups’ (ibid:205).

The nurse

The doctor’s episteme is largely based on the paradigm of scientific knowledge. The nurses have in addition some other perspectives. The nursing history as described by Sandelowski (2000) is sequentially aligned with the view of the woman in general in our society. Sandelowski basically focus on the introduction of three technologies (the thermometer, the syringe, and complex monitoring technology) in the nurse work, and how the nurse gradually took “command” of the use of this technology, i.e., appropriated it both to the best for patients and organization. The nurse is also often the seen as the physician’s third eye and extended arm, and that machines moved nursing forward from ‘intuitive care to intelligent care based on scientific knowledge, a

goal toward which nursing leaders and scientifically minded nurses had always aspired' (ibid:123), and this 'mastering the mysteries of machine technology was viewed as moving them closer socially and professionally to physicians' (ibid 127), which again, 'stimulated collegiality, collaboration, and a "more equal" relationship between nurses and physicians.'(127-128) The nurse often balances between cure and care, between psycho-social understanding and technical solutions. They create social environments by taking the sharp edge of the technology while they focus on pro-longing the caring factor also when technology is replacing manual paper journals. This could be seen as what Moen (2002:93) calls 'professional socialization and adoption of nursing culture', in that, 'prevailing norms, beliefs and values of nursing' is 'started in the educational program and reinforced in clinical practice.' (ibid) They are also conditioned by the "normality" of disease in that disease has become a normal "everyday-thing".

Lay people as patients

Regarding the lay people, Wiener et al (1980) draw up certain implications of the "tighter" integration between patients and doctors, starting with two" extreme" viewpoints. The first implies that patients have the right to know everything, and that the physicians are arrogant. The "power imbalance" viewpoint is basically that 'the unequal status inherent in a professional-lay relationship serves to reinforce the professional arrogance at the expense of the lay person.' (ibid: 31) The second focus on the physician's point of view, saying that providing patients with information has a psychological effect and thus give side effects of unwarranted anxiety (ibid:32). This point of view continues saying that when 'the technical jargon of law is imposed on the technical jargon of medicine a deadly combination occurs' (ibid: 33). Strauss et al opposes these two arguments saying that safety is the most important, and although the medical technology creates a more and more complex situation, it will not necessarily make it better that patients themselves regulates everything during the treatment process (Wiener et al 1980). The issue should, rather than question the arrogance of the physicians be, how does 'specialization and dispersal of care doing both to the physician's role and the patient's care' (ibid: 35). There is however problems related to patient power seen from a medical point of view. The creation of many different patient groups with expertise on several areas has increased by the arrival of Internet, and there is an importance in focusing on additional aspects like how should the hospital

together with these groups enable improved distribution of information to the individual patients. Table 1 gives a brief overview over matters discussed and literature referred to.

	PERSPECTIVES	LITERATURE
Scientific	Embodied and encoded Universal decontextualised Rational and controlled Realistic Based on training and experience	Technological conception of disease (Hoffman 2001) Reflexive knowledge creates less control (Giddens 1990) Nurse balance between professionalism and individuality (Sandelowski 2000)
Lay	Embodied and hardly ever encoded Based on feelings and local knowledge Contextualised Empiric and partly uncontrolled Pragmatic	Lay people as “local experts” (Wynne 1996) Pros and cons with lay focus (Cerezo and Gonzales Garcia 1996) Patient power elements (Wiener et al 1980)

Table 1 : Overview of scientific and lay perspectives with literature used above

Balancing the individual and the universal: Implications for the embodied knowledge in the professional bureaucracy

So far I have talked about knowledge types as embodied, embedded and encoded. The embodied knowledge is obtained, used and increased through practice, and assisted by locally stored information systems like clinical technology etc. The embodied knowledge of the clinicians and the nurses has always elements of “universal” knowledge. This has increased in the era of modernity which brings with it sophisticated technology. The expert has difficulties in constantly obtaining new information, and has lost some of its trust amongst lay people. This type of focus enables a view of the embodied knowledge of the surgeons or physicians as different from the embodied knowledge of parents and patients. The professionals are conditioned by an aspect which Mintzberg (1983) calls pigeonholing. “Pigeonholing” implies building and maintaining categories, as it would be an enormous matter and take a huge amount of resources to treat every patient as a unique case (ibid: 192), and thus, ‘in the professional bureaucracy, diagnosis is a

fundamental task, but it is circumscribed. The organization seeks to match a predetermined contingency to a standard program. Fully open-ended diagnosis – that which seeks a creative solution to a unique problem – requires a third configuration (adhocracy)’ (ibid: 193). The pigeonholing concept can be seen as a part of the market-economical logic and is embodied in the professional knowledge of the physicians (and the nurses). The depth of the embodied knowledge is challenged and interfered by the constraints of performing across several patients; individual service is challenged by serving as many as possible. Figure 1 (below) demonstrates that professional hospital widely across several individuals, while the individual patient has depth knowledge on her specific situation.

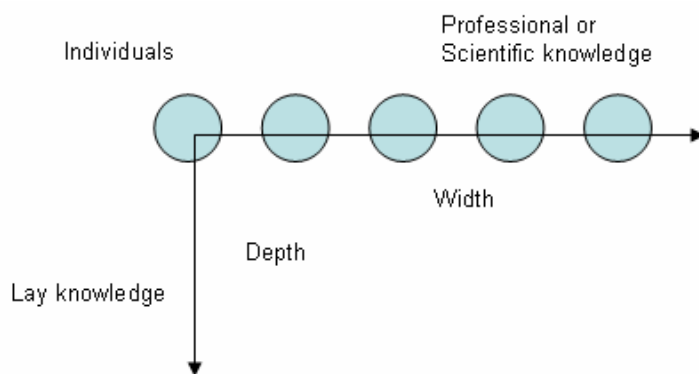


Figure 1 : Professional and lay knowledge

The embodied knowledge of professionals is basically obtained in practice, through negotiations between workers who solve “everyday” problems. In this knowledge creation, use and distribution of technology is an integrated actor which on the one hand enables re-design and efficiency, but which on the other hand can lead to initiatives that focus on explication and encoding of knowledge. This might threaten the flexibility of the professionals at the clinic. Lay people like patients or parents have also some type of embodied knowledge, but this is different from the professional knowledge of the hospital workers. The professionals treat patients based on pre-defined categories in which patients are positioned. The EPR tools enable efficiency measuring which amplifies this perspective. The lay knowledge is based on personal and local factors related to unique individuals. In addition the professionals are not a common integrated group but consist of different practice communities which have specific abilities that are used across the communities in treating patients.

When workers obtain new knowledge, like new operation techniques or how to use a technological artefact etc, the existing competency is challenged by the experience each one of the worker has. That is, a tension between the existing competency and the new knowledge or experience arises. This tension enables a collective learning which is continually dynamic. The decontextualised expert knowledge within the hospital is increasingly challenged by the contextualized lay knowledge from “ordinary” people. Some perspectives of this distinction have been given.

In summary, organizations consist of knowledge workers who shares knowledge within their communities. Organizations have however as it’s task to also perform products or services to customers. In order to perform such servicing they have to collaborate, that is, they perform across different communities, and exchange knowledge in practice on different parts and aspects of the treatment process. In relation to this a theoretical framework which outlines this across-communities perspective is needed, and the relational framework of Actor-network theory is thus outlined in the next section.

2.3 Actor-Network Theory

The theoretical framework of ANT is a result of Michel Callon and Bruno Latours work in the 80’s at Ecole des Mines in Paris. ANT enables a description of different actors, both humans and non humans (like technology), as working together performing action. ANT ‘is concerned with investigating the social and the technical taken together the creation and maintenance of coextensive networks of human and nonhuman elements [actors] which, in the case of technology, include people, organizations, software, computer and communications hardware, and infrastructure standards.’ (Walsham 1997:466,467) The action consists of performing expertise in different parts of, and on different points of time, in a process. Law (1992) claims that all our communication is mediated by and through objects and that social network are created through interaction between humans and other material. The order (in social networks) is then ‘an effect generated by heterogeneous means.’ (ibid: 3) Actor-network theory thus gives us the ability to look at action as networks of relations between several actors. It enables a description of different knowledge systems, professionals or lay people, as acting together on the treatment

process. The framework does also provide a rich vocabulary for description of complex processes.

Because ANT is not a stable and unified body of knowledge, and because the authors often extend and revise the model adding new concepts (Walsham 1997), it is important to use the concepts that are interesting in relation to the specific case study. I will by using the relational aspect where actors meet across communities creating networks which perform action, describe the process through a four step translation process, and adding the aspects of multiplicity and interference use of classic and new ANT together. First I will describe ANT concepts in relation to knowledge. Then I will describe the four steps in creating the “translation” process outlined by Callon (1986), before I give some key concepts of ANT which will be used in my story. An outline of these aspects will then be summarized below.

2.3.1 Early ANT and knowledge

Regarding the concept of knowledge one can say in ANT terms that it ‘is embodied in a variety of material forms’ and that ‘it is the end product of a lot of hard work in which heterogeneous bits and pieces -- test tubes, reagents, organisms, skilled hands, scanning electron microscopes, radiation monitors, other scientists, articles, computer terminals, and all the rest -- that would like to make off on their own are juxtaposed into a patterned network which overcomes their resistance. In short, it is a material matter but also a matter of organizing and ordering those materials.’ (Law 1992:2) Knowledge could then be encoded and embedded in diverse material artefacts, like information systems, or embodied in human beings, like the physician or the nurse. When analyzing the network to understand different workers, how they work, how they communicate, it is then important to investigate both the human and the non-human actors. In addition, different knowledge communities have their own culture, interests and focus. Although they might be very different, they obviously have relations as well, in that they interrelates in daily work performing cure and care for the patients. ANT enables us to look at the different workers and communities, and how objects are a part of the practice, while using the same vocabulary. This is what Callon (1986) describes with three principles: describe, not judge the

way the actors analyze the society; use one concept repertoire in the judgement of the description of nature and society, that is, generalized symmetry; and repudiate the border between natural and social events, follow the actor, free association. ANT does then provide a solution to the problem of giving an integral theoretical understanding which includes both the technical artefact and its surroundings, and it does so without the use of explanation models which favours and theorizes either the social or the technical aspect (Bygstad and Rolland 2004, my translation)

2.3.2 Four steps of translation

In order to create a coherent network which collectively performs action, different interests have to be translated. The step-wise process of translation will next be described briefly.

According to Callon (1986), the translation process is the process that creates a “space for action” through four steps: the problematization; the interessement, the enrolment, and the mobilization of allies. The **problematization** is a system of alliances or associations between entities (actors or communities), which defines their identities and what they want. The **interessement** is about how allies are locked into place. This part of the process of translation contains a focus on how actors submit, that is, participates in the initial plan or inversely how they refuse the integration ‘by defining its identity, its goals, projects, orientations, motivations or interests in another manner.’ (ibid: 207) If the actors’ local interests are not taken into account, they might refuse to cooperate. The interessement is then about, for one actor-unit, trying to impose and stabilize the identity of the other actors (ibid). But the other actors could have alliances elsewhere, that is, have other competitive problematizations, and this could give the other actors other interests. There are several strategies which could be use in order to “secure” the interessement we have: pure force, seduction or stimulations. The interessement will not be statically achieved once and for all; it will be a continuous process to maintain this interessement. The **enrolment** describes how ‘interessement achieves enrolment if it is successful. To describe enrolment is thus to describe the group of multilateral negotiations, trials of strength and tricks that accompany the interessement and enable them to succeed.’ (ibid: 211) Actors are enrolled when their interests is tried “covered” through negotiations. Conflict occurs when ‘the actors implicated do not acknowledge their roles in this story nor the slow drift in which they had participated, in their

opinion, wholeheartedly.’ (ibid: 224) Last, the **mobilisation of allies**, concerns how there often is only a few individuals which participate (as spokesmen or delegates, for others), and how a central actor mobilizes these allies in order to obtain “success”. What started as a fragmented problematization, with many discussable hypotheses about identity, relations and goals, regarding the different actors, then turns into a “neat” network of relationships (Callon 1986). But there is no safety yet, the network must be continually cultivated, it can be contested any moment.

2.3.3 Detours

The concept of detour enables a description of deviance from a straight line. The treatment process is continual and dynamic and not defined before-hand. The translation of interests may lead to deviances. The different interests interfere with one another and create detours. A detour is usually seen as a ‘deviation from an original plan or interest, and it emphasizes the need to form alliances with other actors in order to be able to act’ (Aanestad and Hanseth 2002:184). The alliances are achieved and obtained through processes of translation of interests. There is however a continual tension between different interests. The negotiation between different actors in fulfilling the translation process creates detours, i.e. the practice is decided through continuous negotiations which decide the further treatment process. The concept of detour (Latour 1999) is then about how subjects and objects, actors, together (through negotiations) enable and creates integrated network with common interests obtained through negotiations. Some aspects of early ANT are summarized in table 2 below.

Concept	Description
Actors	Human and non-humans
Enrolment	Negotiation program of getting actors to participate in the network
Translation	A process of problematizing, interessement, enrolment and mobilization of allies in order to align humans and nonhumans to the actor-network

Delegates	Actors who stand up and speak for particular inscribed viewpoints
Alignment and co-ordination	A ‘successful’ translation creates an aligned and co-ordinated network. Alignment and co-ordination is thus about how the different actors are balanced in the network
Inscription	The way use-patterns is indicated in technological artefacts or/and organizational, written or unwritten, rules, norms and regulations ⁴
Detour	Deviation from an “original path” created by the occurrence of “new” agents which enables reconsiderations. (or new goals)

Table 2 : Description of early ANT concepts

2.3.4 Later ANT

While early ANT focus on how to study networks of relations between actors, and how the four principles of problematization, interessement, enrolment and mobilization is used in translating different interests into ones own, the later ANT deals with the complexity of networks and relations. Hanseth et al (2006), claims that early ANT was ‘focused on how one single-actor network was aligned by a dominating central actor’, while keywords in later ANT are ‘multiplicities, inconsistencies, ambivalence and ambiguities.’(ibid: 13) This shift is related to the focus that ‘the web [that is, the world of happenings are complex, uncontrollable and inconsistent] will not stay still’, and that ‘perfectionism is dangerous’ (Law 2003:11). The ‘managerial focus’ of the early ANT has been replaced by increasing focus on dynamics, complexity and reflexivity. To extend early ANT with concepts from later ANT is thus done in order to better understand the dynamics of contemporary society. Law outlines three implications for better describing this ‘imperfectionism’. First, ‘new forms of cartography which represent instabilities, fluidities and partial coherence’ which are better than the existing dimensional ones,

⁴ I claim that inscriptions can be both ”inscribed” technically in technical artefacts, and “pushed” onto people by written or non-written rules, norms and regulations

is required. We need to map ‘flows, flexibilities and variation’ in a way that ‘any hope of mapping everything using a single technique to obtain overall view is misplaced’. Secondly that leadership in multiple connected organizations and systems has to focus more on ‘local interferences’, i.e. an understanding of that different actors and networks interfere with one another in overlapping, intertwining, integrating, and that this sometimes is conflicting. Thirdly, that one needs to challenge the assumption that the demands from the general view, regarding the speed and speed of change, have to be followed (ibid: 14). Implications of this is then that the earlier managerial focused (which in Callons 1986 was described as fragile anyhow in that the fishermen protested at the end) has to be replaced by an increased understanding of multiple interests. The multiplicities do not necessarily have a universal logic but rather logics which relates to different local sub worlds. In order to translate these interests, different ontological perspectives may be used.

2.3.5 The translation of multiple interests

The translation of interests outlined by Callon (1986) is a four step process. The four steps contain important perspectives in understanding how a central actor persuades, satisfies or motivates (some might say seduce), other actors to follow them. The central actor could be (often is) an obligatory passage point which is a point through which other actors have to pass. The central actor could also be one of the delegates. Delegates are ‘actors who stand in and speak for particular viewpoints which have been inscribed in them.’ (Walsham 1997:468) That is, delegates could be actors who have interests which relate to interests other actors have. A patient at a hospital could have both physical and psychological needs in relation to the treatment, and it can be that different actors provide particular viewpoints which relate to the different interests the patient have. However delegates do not necessarily have to be human actors. It could be that data from a survey, visualized by graphs or numbers, which can be used as “evidence”, and can thus be called delegates for the reason that they speak of certain facts. The “objective” quality of operation or treatment techniques could further be strengthened by research which confirms the “success-rate” of these techniques or methods. In this way hypotheses are tested and verified, and “objective facts” are found which could strengthen the hypothesis.

The amount of success, i.e., the degree to which we obtain a successful network of aligned interests depends on how the ‘enrolment of a sufficient body of allies, and the translation of their interests’ is performed in order to get them to ‘participate in particular ways of thinking and acting which maintain the network.’(ibid: 469) The degree of success then profoundly depends on how the actors’ interests are dealt with.

Translation has to be done between different interests both amongst the professional and the common people. There is not one aligned mode of ordering which suits them all and which help aligning the network. Each individual patient has her own specificities. The individual specialities have to be understood together with more universal aspects. The universal aspects relates to the generalities regarding a disease. Diseases like tumour or synostosis (see Empirical chapter for details) have several pre-definable aspects which can be identified by the doctor using his or her knowledge. These (and other) diseases have however specific individualities as well. These individualities are not necessarily compatible with universality of objectivistic professional knowledge. In order to grasp these individualities, as Law (2003) indicates, leadership has to be focused on the local interferences or specialities.

The human actors thus have a set of interests. I claim that these interests are related to three main focuses amongst patients and parents⁵. These are the knowledge on *physical appearances* of them self or their child, and how this changes; it is the knowledge about *psychological conditions* both related to general anxiety regarding the disease and the ontological security of the individual (what Giddens 1991 calls the influence of the protective cocoon); and it is about the *socio-economical* interests of the patients or parents which relate to their own social or economical situation, and that several factors regarding this may interfere with other interests. Some of these interests are related to passions or feelings, while others regard more rational social economical factors. The balance between these three aspects of local knowledge can be seen as what Cussins (1998: 169) calls a ‘constant ontological dance between ourselves and our environments’. We tend to objectify and subjectify ourselves in different situations, and in order to manage happenings that may occur to us. I do not, as Cussins does, analyze the different aspects of the

⁵ The patients I write about are with one exception children. It is then their parents who stand up and speak for them in the treatment process. I will talk more about this in the empirical chapter.

objectification of the self, but rather bring forth different perspectives in addition to the “purely” medical or physical ones. Law and Singleton (2003) describes about how objects (like diseases) have aspects which are absent or present (or both). Aspects of what is present are always in addition absent. If a lay person possibly has synostosis the doctor has to investigate what type of synostosis it is, and the degree of the disease (operate or not?). Further the disease can have several additional factors. It can affect the proper growth of the brain, it can create an inclined form of the head which could affect the vision, the growth of teeth, and so forth. What can initially be absent in the doctors focus can suddenly be turned into focus. This regards also social aspects of the disease. Regarding a brain tumour the rationality of cure is not always enough. For the doctor it might be enough to focus on the elimination of the object, the tumour. But for the subject who suffers the tumour several other aspects can be present. This can imply psychological aspects related to the fear of dying, or to the fear of being disabled. The rationality of cure can have limits in that absences are taken for being non-existent or being looked at as irrational and irrelevant aspects. The patient can to some extent be important in identifying some absences.

These additional perspectives are of interest for both doctors and patients, especially because, as Wynne (1996) notes, ‘expert systems have a tendency to operate with unreflexive blindness to a problematic and inadequate model of the human’ (ibid: 68)

Regarding the scientific or professional personnel, they have as well additional interests. We have earlier seen that the scientific paradigm inherits some basic assumptions of the reality. We have also seen that this reality is reflexive and that the scientific knowledge is sometimes inadequate, as its basic assumption rests on stability and control in eras which are partly uncontrollable. The clinic was created in order to detach diseases and epidemics from their “natural” context, and is based on the focus on cause and effect. The scientific expertise is also conditioned by the increasing focus on efficiency while quality is maintained, and on evidence even though evidence is not easily seen through the technological lens. This creates time constraints, and budget focus which can interfere with other more qualitative interests. “Pure” science does not exist; political, economical, and social factors interfere with the scientific practice (Latour and Woolgar 1979, Latour 1987).

2.3.6 Interference and multiplicity

When there are multiple interests or logics (based on professional or lay knowledge), interferences may occur. The maintenance of different interests or viewpoints is not an uncomplicated, but an important task. Even if there are obligatory passage points and delegates, which can be seen as structural and institutional paths “enforced” on patients by the health system in order to predefine the way to treatment, several different interests and crossing logics can hamper the effectiveness of the obligatory passage points. These different interests, or logics, are not easily defined or understood when the treatment process is seen as a straight line of sequential happenings which easily are “zipped” into each other. The different interests do in fact often create interferences, in the sense that they interfere with what is traditionally seen as a straight line process, and questions the correctness of this pre-order treatment line. These interests are interfering with the straight line process view when they question the decisions or perspectives claimed by the central actor. In addition, the central actor has seldom straight line perspectives, or interests, himself. Both the participating actors and the central actor are thus actually refusing the straight-line assumption. This admission has certain implications. First leadership in multiple connected organizations and systems has to focus more on “local interferences”, that is, an understanding of how different actors and networks interfere with one another in overlapping, intertwining, integrating, and that this sometimes is conflicting (Law 2003). Secondly, even if different actors have different interests, which sometimes interfere with one another, this is not necessarily a question of many individual decontextualised interests. Rather it creates a multiplicity ‘where the various formation of an object may collaborate and even depend on one another’ (Mol 1999). It is not a question of a mere destructive anarchic reality where interests are objects which create only fragmentation and where we should let these fragments live their own life. It is rather that that these fragments or objects, or interest, which has similarities and affiliations which sometimes collaborates and “makes order”. An example of this is when the doctor identifies patient interests, focusing on integrating these interests whilst in the treatment process. The result of cooperation between the generic focus of the doctor, and the special localized focus of the parents or patients can sometimes make complex interferences between different interests, but it will also create a situation where the different interests can be aligned

with one another in making a successful trajectory. Aspects of late ANT is summarized in table 3 below.

Concept	Description
Fluidity	In opposition to streamlined and structured flow of information, fluidity is about flow + change
Multiplicity	Multiple interests may interfere, but are also dependent on each other
Interference	An interaction between different effects, ordering processes, which (can)creates disturbances and thus unwarranted effects

Table 3 : Descriptions of concepts from later ANT

2.3.7 Knowledge as enactment

I have so far stated that the treatment process is a matter of identifying and translating different actors' interests. Further we have seen that to create a coherent network of aligned interests (a successful translation), we have to understand that there are interfering interests, or logics, which sometimes collide, and other times are integrated into one another in multiplicities. Identifying interferences and multiplicities presupposes collaborations between different actors, and identification of interests amongst these actors. Law (2000) says that knowledge can be about negotiating between different actors (experts and lay people) in identifying a "good solution", but is also about producing 'an object, which is, something known or known about', and that this process simultaneously 'produces a subject, something or someone who does the knowing that corresponds to what is to be known.' (ibid: 349) One of the important features of actor network theory is, as mentioned earlier, the common symmetry between humans and non-human actors. The knowledges, and the objects that they know, could thus be seen as being produced together (ibid). Law notes further on that these materially heterogeneous processes which create knowledge and objects to be known are effects, or relational moments, not substances. 'What is, as well as the knowledge of what is, are produced together.' (ibid: 350) The treatment process is then about how the different knowledges and objects to be known is called upon in relational

moments, and how the different aspects of knowledge is understood and translated into the relational process.

In summary we can say that I have so far outlined several different perspectives of knowledge, and identified epistemological fundamentals. The view of knowledge as embodied, embrained, encultured, embedded and encoded, also in institutional objects and material is a view I can subscribe to. This applies to the knowledge of both the professionals and ordinary people. After I defined how knowledge can be viewed in practice as an enactment between different actors, I described communities of practice and how a patient treatment process creates a “meeting point” between different communities enacting on the treatment. The early ANT framework outlines a process for enrolling actors into a network in order to create stability. This has to be complemented with perspectives from later ANT in order to describe contemporary “reality” with multiple interfering interests.

2.4 Theoretical contribution

In my thesis the aim is to support the view of knowledge as complex and deeply related to the context. Knowledge is a part of practice, and it is difficult to explicate semantically. Knowledge is obtained through continual negotiations, collaborations, discussions and communication in practice, at work. Information systems consist of both technical and social aspects, and have to remain that way when part of the practices are explicated and encoded. My contribution is how professionals and lay people actually may obtain a common agreement based on the alignment of multiple interests. These interests are highly conditioned by several factors, including technology or/and changes or structures caused by the re-configuration of manual processes as a part of technological implementations. The interests uncover several aspects related to different perspectives amongst the human actors. These perspectives, or knowledges, have to be taken into account in order to enrol the actors and continue the process. The concepts of translating multiple interests are thus demonstrated in interaction between doctors and the patients. The theoretical framework of ANT enables a micro description of this interaction through four steps. The findings from these analyses can be used to create theoretical understanding of the process of enacting the treatment.

RESEARCH APPROACH

This chapter contains three sections and several sub-sections. First I will briefly describe some elements regarding the empirical/theoretical “nature” of the thesis and then introduce the setting where the fieldwork took place. In section 3.3 research methods are introduced and briefly discussed. This includes both the epistemological and the theoretical foundation. Section 3.4 contains the research techniques used, and these are discussed. Finally there is a reflection on my own role as a researcher in relation to the field, and on how the work evolved.

3.1 Empirical theoretical thesis

In this section I will draw up some general aspects regarding my work. My thesis is not a case study where the research approach was designed first, and then carried out according to the design structure. My thesis contains a decent amount of fieldwork, but is conditioned by the hermeneutical movement between theory and empiricism as my knowledge of the field, and the findings from the fieldwork was constantly in movement. I am investigating knowledge work, the heterogeneity of medical work and the interaction between professional and lay people, because I think it is a under focused issue, it is an interesting issue and the theme is as well very inspiring for me. There are however some constraints. It is a demanding theme with many sociological as well as philosophically discussable aspects. Information Technology and Information Systems are today deeply integrated in human practices, and it is difficult to separate the knower from what he or she knows. In this type of knowledge work, the actors, the communities and systems are integrated mechanisms. This enables a possibility to “attack” the issue from many different angles, and my “humble” work can only give some perspectives in this complex material. A second constraint is the time. A master thesis has a limited scope.

In this first section I will describe this changing focus in my research, before I give examples of how the work evolved.

3.1.1 Changing focus in my research

My initial aim, when I did my fieldwork, was to observe doctors, nurses and others while using the Electronic Patient Record through a computerized work station. In the first observation session, which was observing patients and parents in interaction with the doctors, I registered something that interfered with my assumptions: the parents and patients were more insistent than I expected. This triggered my curiosity: do the parents and patients have more knowledge than before? Is this a problem at the hospital? Is this due to information gained from Internet? And what is the nature of this local knowledge? In later observation sessions, I also noticed that the knowledge of the individual worker and the collective group of workers was based on an insistent use of different artefacts (paper, phone, EPR, other information systems, mail, CD etc). I then wanted to investigate this as well, and my thesis thus implied both looking at use and distribution of knowledge through different artefacts (objects), and the implication of persistent patients and parents.

I have in this chapter both related my research to philosophical fundament, and described what theoretical perspective I see myself as belonging within. The research questions were seen as being of a type which required an interpretive research as it contained focus on working practices and knowledge in practice as interpreted by the informers. Further, the interpretive approach was seen as very convenient when observing and interviewing parents and patients. Finally data analysis techniques were outlined, and the elements from the hermeneutic circle were related to aspects of my work.

3.1.2 How the work evolved

...hermeneutic process of changing assumptions

The hermeneutical circle is both about the circular and iterative way the researcher works in order to understand the context, and assumptions that every person brings along to the field. The assumptions of each individual are conditioned by historical elements. Materstvedt (1999) says that 'the hermeneutical circle, which indicates that each understanding necessarily is a contextual understanding. We can never repeal our own historicity, and this recognition of our own limited horizon is what we have to think with when we interpret... in other words it is impossible to be

without supposition' (ibid: 58). This supposition has to be reflected upon in order to understand that the constraints the history constitutes and also that the researcher's presence affects the informers.

Further, I will make a brief example of the evolving "nature" of my interpretive research. Initially, I noted that Internet was much criticised by informers like nurses and doctors:

From observations:

I1 "Internet makes the patients frightened"

I2 "Internet gives patients information which is impossible for them to understand medically"

From Interviews:

As I "discovered" the "institutional tendency" to look at Internet as problematic I could meet this type of statements with "explorative" questions like: *how does this affect the interaction?* They would answer: they [the patients] are much more "pushy" now than earlier. *What do you mean by pushy?* They do not give up, they demand answers. They focus too much on future hypotheses. *Why is that a problem?* Because the portioning of information is important, the patients and parents have to receive the information that is relevant for them.

Further interviews:

Patients sometimes have explicit interests which interfere with the physicians' initial plan, that is, they are important participants in developing a treatment process. Without knowledge and integrity based on their local situation, and a more "aggressive" strategy than traditionally in the interaction with the physician, some treatment processes could have a less successful outcome (more on this in empirical/analytical chapters)

My point is that the phrases, the parts, are investigated through an iteratively hermeneutical process where "old" knowledge is seen in the light of "new" knowledge, which gives the phrases a new understanding. In addition, it is not necessarily Internet alone which is the problem, but the information gained from Internet. And then it is not the information in itself, but the information

in the specific setting. The patient and parents may have right, but they are just too “pushy” on busy workers, hence, the workers feel that this is pushing their already tight schedule. These findings and the understanding of its “nature” could help creating generalizations like: *how can we try to integrate parents’ and patients’ lay knowledge in the treatment process, without interfering with the important issue on how to cure the same persons*. These aspects are analyzed further later in this thesis.

3.2 Case setting

In this part I introduce the setting for my fieldwork. Brief descriptions of the hospital and the specific department are provided.

3.2.1 Rikshospitalet

My research site was the medical institution Rikshospitalet, established in 1826 and being a region hospital in Helse Sør and for some patients in Helse Øst. Rikshospitalet also has extensive functions at a cross-regional and national level. Rikshospitalet is a expert hospital with several ‘highly specialised functions like organ transplantation, bone marrow transplantation, specialised heart surgery of children, and specialised neurosurgery’ (Boulos 2003:30). In addition to the general serving of the Helse Sør and some parts of the Helse Øst region, Rikshospitalet also treat the Norwegian Royal Family. In a clinic like this, medical research is an important matter, and Rikshospitalet has several educational tasks in collaboration with the University of Oslo. Rikshospitalet has approximately 4000 employees (2001) approximately 7,000 rooms, 585 beds, and a patient hotel with 90 beds. Key figures show that 28,000 patients are admitted annually to Rikshospitalet as inpatients, 17,000 patients are given day-treatment, and there are 130,000 outpatient consultations (ibid)

3.2.2 Neurosurgery department

The neurosurgery department is a department within the new clinic called the neuroclinic. Other departments within this clinic are departments for neurology, epilepsy, and psychosomatic sufferings. The neurosurgery department performs diagnostics and treatments of diseases, defects, and injuries in the central nervous system. Because Rikshospitalet is an expert hospital with some of the most experienced surgeons in Norway regarding the before mentioned type of diseases, the department has a big workload leading to a hectic and busy working environment. In all 27 doctors, 140 nurses and 27 administrative personnel are employed at the department. . In addition the department have a head of office, and 6 extra personnel, in total around 200 employees. (MA-J-270206)

The sections of the department which I studied were the out patient clinic, the post section of the children unit, and the intake office. The nurses at the post are divided into three teams; two of them work around the post-operation room, the third in the surveillance room (newly operated patients etc). The number of beds is in total 60 in the department, approximately 15 of them in the children unit.

3.2.3 Additional information

The informers in my fieldwork are with one exception from Rikshospitalet. In addition I interviewed a girl who had been operated at St. Olav's hospital in Trondheim.

3.3 Research methods

In this section I will first introduce some philosophical foundations of research, before I identify theoretical perspectives which my work is localized within. I find the identification of philosophical foundations important as research has several different assumptions attached to it, and a clarification in relation to personal positioning is relevant. Further, I will describe aspects of the theoretical perspective of interpretivism.

3.3.1 Underlying philosophy of research methods

Crotty (1998) states there are initially two questions we particularly want to answer when developing a research proposal, first what methodologies and methods we would like to use, and secondly how we justify the choice of these methods. Our choice of methods, Crotty continues, ‘reaches into the assumption about reality that we bring to our work’ (ibid: 2), and includes hence implications for our theoretical perspective and our view on what human knowledge is and how it can be described. The two questions have then turned into four and include which methods and methodology we will use, what theoretical perspective lays behind these choices and what epistemology informs this perspective. (ibid)

Crotty further elaborates these four fundamentals. Research methods are not only about what we do (carrying out interviews or observation) but how we do it (techniques and settings). The Methodology is the collection of methods, the strategy, linked to the desired outcome while the theoretical perspectives describes our assumptions and how we try to reflect on these assumptions as they change during fieldwork. This implies then first what our view on the area which we work in is, theoretically, secondly which methods we choose to explore this field with, and thirdly how our view on what knowledge is, how it is gained, used and communicated, epistemologically.

The three epistemological fundamentals from Crotty has been outlined in the theory chapter, and is briefly outlined in table 4 (below) The starting point for research is however “real-life” issues, units of analysis which needs to be found, issues that needs to be further explored using interviews and discussions. It is this way the epistemological and theoretical perspectives are linked with “everyday life” issues like methodologies and methods. Crotty continues saying that the difference between qualitative and quantitative research occurs at the level of methods, not at the theoretical or epistemological level. Crotty claims that one can use quantitative methods without being positivistic, but we cannot be both objectivists and constructivists (for example) at an epistemological level. We need to be consistent. Table 4 gives an overview over these briefly discussed matters. In a field study where subjects like human beings and objects like technology together performs action; it can be argued that constructionism is an appropriate epistemological fundament. In the next section I will describe how this applies to my study.

Epistemology	Theoretical perspectives	Claims
Objectivism	Positivism	Objective reality exists
Constructionism	Interpretivism	Different people, different meanings. Subject and objects are “partners”
Subjectivism	Post modernism, Feminism	Subject imposes meaning on the object, and the object do not constrain this

Table 4 : Overview epistemological fundamentals

3.3.2 Interpretive research

In order to investigate how knowledge is accomplished, used, and distributed in relation to the patient treatment process; how Information Technology is used in this knowledge work; and finally how parents and patients behave in the interaction with their doctor in order to secure their interests, an interpretative approach is needed.

We have already noticed (table 4) that the philosophical fundament of interpretive research is in the view that people have different meanings, and using objects in their construction of reality, that is, subjects and objects are partners in the generation of meaning (Crotty 1998:9). The roots or underpinnings of interpretive research include interactionism (Crotty 1998), phenomenology, ethnomethodology and hermeneutics (ibid, Walsham 1995, Mingers 1984), while the “higher level” inspirations are from ethnography and anthropology (Walsham 1995). We can see from this that it has to do with interpretation of other people’s interpretations, feelings, cultural aspects and organizational contexts. According to Klein and Myers (1999) ‘interpretive research [can] help IS researchers to understand human thought and action in social and organizational contexts; it has the potential to produce deep insights into information systems phenomena including the management of information systems and information systems development.’ (ibid: 67)

When the working practices of different actors, and the knowledge they have in order to perform these practices in the best possible way, is the research issue, it can be argued that interpretive research is more “convenient” than a positivistic inspired tentative. Klein and Myers state that IS

research is interpretive when ‘it is assumed that our knowledge of reality is gained only through social constructions such a language, consciousness, shared meanings, documents, tools, and other artefacts.’ (ibid: 69)

In a positivistic perspective, where evidence and facts are collected from the objective reality, research can be performed using surveys; generalized questions etc, analyzing these in relation to pre-defined hypotheses. In subjectivism interviews have to be interpreted, but the subject is superior to the object. Subjectivism is not well-aligned with the common symmetry principle of ANT. ANT investigates the mutual influence between humans (subjects) and non-humans (objects), while subjectivism states that ‘meaning comes from anything but an interaction between the subject and the object to which it is ascribed.’(Crotty 1998:9) To gain understanding of the different knowledges (in the theory chapter, I talked about knowledge perspectives, knowledge in practice generally and in medical work more specifically) a “deeper” intervention into the daily practices, the viewpoints of the human actors, how they use the different artefacts (non-human objects) in their work, and what they “feel” when performing it, has to be performed. The epistemology of ANT is thus positioned within constructionism where subjects and objects are partners and ‘truth or meaning comes into existence in and out of our engagement with the realities in our world.’ (ibid: 8)

Interpretive research provides advice regarding types of techniques and methods as well as how to focus on the role of the researcher, how to collect “evidences” from interviews and what reporting methods to use. The **first** describes how the researcher should reflect on her or his own role in the research, and when the role of the inside or outside observer will be convenient. The inside observer is a role which implies direct involvement in working practices of the subjects under research. This could be very insightful, but time-consuming. An alternative role is that of outside observing which enables more distance. The choices will obviously affect the way the researcher is viewed at by the research subjects. The **second** principle is about research methods. Walsham (1995) argues that ‘with respect to interpretive studies in case studies as an outside observer, it can be argued that interviews are the primary data source, since it is through that method the researcher can best access the interpretations that participants have regarding the actions and events which have or are taking place, and the views and aspirations of themselves

and other participants.’ (ibid: 78) The interviewing style should be balanced between ‘excessive passivity and over-direction.’ (ibid) There are several reporting medium for “capturing” human beings interpretations. Two of them are: tape-recording, which enables a full transcript of everything that was said and extensive note-making, where the notes afterwards is written up by the researcher. The first provides a full description, but can hamper the subject from talking “naturally”, and requires extensive transcribing after the interview. The second requires more notes taken during the interview, and what was said is only partially captured. The latter may enable a more “casual” atmosphere between the researcher and the subject (ibid), in that the informers is not “monitored” and taped. Note-making can also condition the interview. A researcher who is busy taking notes can affect the “flow” of the conversation. In addition to these mentioned methods, e-mail questions provide a good resource. The **third** principle: reporting methods contains focus on interpretive researchers as not reporting “facts”, but interpretations of other people’s interpretations. (ibid) Walsham suggests ‘that we at a minimum should report on details of the research sites chosen, the reasons for this choice, the number of people who were interviewed, what hierarchical or professional position they occupied, what other data sources were used, and over what period the research was conducted.’ (ibid: 79) In the fieldwork section I will describe my use of these three principles in my research (see next section)

In the research approach, data gathered from observations and interviews is interpreted in the light of workers knowledge, researchers role and knowledge, and also by focusing on how a researcher (with limited knowledge) “learn” through the process, and see things in new ways. In order to receive information from the human actors regarding their feelings, interests and focuses - which are not objective facts but subjective interpretations of their situation – the research approach must enable different questions to be raised to different informers. The ability to ask questions ad-hoc regarding issues which arise as a part of another question is one of the main aspects of interpretive research.

3.4 Fieldwork

Early in January 2005 (the second term of my master study) I got involved in the Rikshospitalet team of the Information system group. This group consisted, and consists, of several researchers (Master students, PhDs and other researchers) who are more or less engaged in health informatics

at Rikshospitalet. The head of the IT department at Rikshospitalet thought that the neurosurgery department was a suitable place to start observations. In order to get access an ID card was necessary and it was also mandatory to sign a secrecy statement. The second term of my master thesis thus implied further on to read background material and starting to arrange observations. The background material was included in the INF5550 (writing course) paper. This course is mandatory for every master student, and is normally performed the second semester of the master study. The observations were performed from March to June 2005. Table 5 gives a brief overview over phases, activities and the outcomes or result of these activities.

Phase	Activity	Data /results
Term 2 January to June 2005	Background information Getting access Organize observations	Transcripts from observations at three sites Identified focus field by defining several themes
Term 3 August to December 2005	Fieldwork, observations and interviews Iterate between theory and empiricism	Transcriptions from interviews Reading of theory
Term 4 January to April 2006	Bridging case and theory Perform additional interviews (e-mail) Determine core contribution Write up, bridge case and theory	Generalizing findings

Table 5 : Overview master thesis phases

In all I performed four observations at different sites at the neurosurgery department, each lasting around 7 hours (totally 28 hours). After these observations (which also contained discussions and talks with several clinicians at the place they work) I arranged the emerging topics of my research into six “clusters”, and chose to elaborate on one of them (these topics can be seen in appendix 1). The third phase, autumn 2005, was used as an extensive interviewing period. I totally performed 12 more or less structured interviews, 10 informal conversations and some additional e-mail and phone interviews. (See table 6) In the fourth phase the main focus was to bridge case and theory, write up, produce generalizations and define contribution. Walsham outlines four

types of generalizations from interpretive research. The first is the development of concepts, the second generation of theory. The third is what Walsham calls the ‘drawing of specific implication’ which is about seeing relations between different aspects (like design, development and business strategy) in an implementation project. The fourth is about contribution of rich insight. In order to bridge case and theory, determine core contribution and trying to generalize findings, additional questions to informants (mainly by e-mail, but also some by telephone interviews if the informants agreed) may be needed. In addition extensive additional reading and re-reading of theoretical issues, as well as re-reading of fieldwork notes and writings are important. Table 5 provides an overview over phases, activity within the phases, and some results from the different periods.

Informant	Informal conversation	Structured open-ended	E-mail	Telephone interviews
Nurses	2	4	7	
Doctors	2	2		
Parents/Patients	1	4	5	1
Secretary	4	1	20	
Head of office	2	1	18	

Table 6 : Overview fieldwork activities

The issue of getting and maintaining access might be misunderstood to be a trivial task, but it is not. For me getting access included “nagging” on key IT department persons at Rikshospitalet to find relevant personnel that I could contact at the neurosurgery department and persistence in maintaining the access once obtained. I tried to use every possible situation to show inspiration, motivation and formation once access was obtained. It is important for a researcher, to have the ability to understand the importance of institutional norms, and behaving responsibly. Such an approach may also make it easier to get access later. The motivation and an inspired approach will also help during the interview and observation sections, as this can trigger eventual inspirations amongst informers as well. The informants were selected after I had performed the observations, and to some extent obtained a brief understanding of the field. The theme I chose to concentrate on involved how the clinicians, use and distribute knowledge in the information

system (which both contains papers systems, manual routines as well as use of IT), and how the patient/parent knowledge made an impact in the interaction with the hospital workers. In order to collect information on this issue, interviews with administration (mainly secretaries), nurses, doctors and parents/patients were performed. I then sent a list to my internal collaborator at Rikshospitalet, and she gave the task of finding and selecting informants to another secretary. Further I negotiated with this secretary in identifying possible subjects for interviews.

3.4.1 Interviews

In order to “identify” peoples’ practices and knowledges in relation to the patient treatment I used an interpretive approach. As noted earlier (section 2.2) Walsham suggests that the nature of interpretive research, being the interpretation of other people’s interpretations of their action, entails that interviews are the primary data source. In relation to this Patton says that an interview is performed because ‘the interviewer wants to see how persons view the program under study.’ (Patton 1987:109) Patton suggests three types of qualitative interviews: The informal conversational interview, the interview guide, and the standardized open-ended questions. The informal conversational interview is typically a conversation that occurs as a part of participant observation. An interview guide is a list of questions or issues that is prepared before the interview. This guide has as its goal to cover the same material for a number of informers. Finally the standardized open-ended consists a set of questions carefully arranged for the purpose of taking the respondent through the same sequence and asking each respondent the same question. This is particularly appropriate when several people are to conduct interviews, and the variations in responses needs to be reduced (Patton 1987). I find Patton’s categorization sound, but have “merged” two of them: interview guide and standardized open ended, into one I have called structured open ended (Table 4). When we perform interviews there are several things that lead us to a preferred type of interview technique. Examples of this are time constraints among workers, that is, how much time is granted, what possibilities there are for interruptions etc. In my situation I basically interviewed four type of informers; administration personnel, nurses, doctors and parents/patients. In relation to this I can say that the administration has the possibility to relatively freely handle interviews within a defined amount of time, without being interrupted very much. The nurses also have the possibilities to grant interviews, but rather say that “meet up

between 10 and 13 o'clock and we can talk when we have the time". That is, they may be interrupted, they do not know when, but has the possibility to give interviews relatively freely. Some of the doctors have very little time for these matters. A maximum of 30 minutes is granted, often much less. In addition they sometimes tend to not show up because of happenings out of their own control or because they have forgotten the meeting. The patients were with one exception children, and I was then performing interviews with their parents. The exception was a girl who was operated for brain tumour when she was in her late teens. The patients or parents was interested in being interviewed, but are spread throughout the country. My interviews was performed at the clinic (before or after out patient clinical encounters), and the patients sometimes had a hurry in getting on to reach a plane or a train. We can thus conclude that interviewing these three groups of workers and "civilians" like parents or patients entails different type of strategies.

Regarding the **administration** I used relatively structured open ended questions. In addition I had informal conversations with them during observations. The observations (see next section) were used to identify issues regarding the subjects knowledge work, the structure of it, how they used Information Technology in their work. In order to understand the activities and the context, informal discussions were performed during observations and questions were created afterwards reflecting on the field notes. These questions, standardized and structured open ended questions, then had the role to further elaborate my understanding of how the administration people work, how and when they call upon other actors and how technology is used in this process. Some of the answers generated further questions which I tried to get answers on by e-mail communication.

Regarding the **nurses** much of the same "strategies" were used. In the observation sessions, I could observe how they performed, interacted, discussed, negotiated and took decisions. In the same observations I could ask them brief questions about what happened, and how they perform certain activities. This was done in a somewhat informal way. When reflecting on the field notes I registered some of the regularities and created questions which could further elaborate my understanding of how they looked at their work, and their knowledge in relation to it. Examples of this are the implications of what they called: increasing amount of patients which requires feedback on specific questions in relation to disease. The increasing demands are interpreted by

most of the nurses as a result of the arrival of Internet technology. I created an interview guide which I used in exploring these matters, that is, elaborating on what they meant by “increasing demands from patients”. The nurses’ abilities and focus on implementing caring factors when moving from paper to digital patient records was another issue that needed elaboration. This elaboration consisted also of e-mail questions where I asked for examples, and they sent it to me as attachments.

The **doctor** is very constrained by time. I was granted two interviews, and had in addition some “small talk” lasting between 15-20 minutes in-between patient encounters, or when the doctor was working. The two interviews, lasting about 25 minutes, are very conditioned by this time constraint. The questions have to be prepared relatively structured before hand, and there is little time for deep elaboration.

The observation sessions helped me, however, to understand some of the regularities in the doctor’s interaction with the patients or parents. In addition, I used the observation as a possibility to ask the doctor questions along the way. To understand the doctors focus further, I asked the administration some questions regarding working tasks of the doctors.

The **parents or patients** are also constrained by time. In addition, they are not professional hospital workers who have specific working tasks at the clinic. Their life might be very influenced by their child’s disease: the disease can change their family life. They can thus be seen as consumers, seeking the best possible treatment, and as lay people who know their specific context. My goal regarding this was to illuminate the parents and patients perspectives in relation to the treatment process, what were their main interests, and then elaborate further what these interests consisted of. This implied first asking specific questions about the interaction between patients/parents and doctors, and secondly asking what was the most important information the parents or patients needed during the treatment process, and how they tried to fulfil these needs.

The form and structure of the interviews thus varied from group to group, both because they had different constrains and different focuses: they are individual communities. In addition, the individual interviews within the same work group varied: the different workers are different

subjects and may respond different to similar questions. Examples of this are the questions about use of Information Technology. The nurse Elaine⁶ is accustomed to work with computer equipment and the answers about how she uses Information Technology may vary from the answers given by Britt. Britt can, however, give insights into difficulties in using Information Technologies which Elaine takes for granted. This can also lead to Britt putting her focus on more “soft factors” in nursing. I tried as a researcher to have open ended questions where the subjects’ answers determined what questions was asked further on.

All the interviews were written (not recorded), and the interview notes were written up immediately after the interviews. Walsham (1995) says that the noting technique has both advantages and disadvantages compared with tape recording, but that it enables a “freer” atmosphere which sometimes is important (tape recording may hamper the informers “will” to talk freely). In the health sector there is much confidential material, and it can be argued that interviewing while taking notes can sometimes be an all in all more “effective” technique because of this.

Limitations

I tried hard to get in contact with more doctors, and I also sent them questions by e-mail. They never responded to the questions, and they were very difficult to get in touch with. My fieldwork is because of this a bit thin regarding the general knowledge work of the doctor. Other limitations are related to the general approach. Even though I have attained both qualitative and interpretive research courses; the learning is also accomplished during active performance in the field. By working with this I have then learned the necessity in being persistent to get access, the need to be polite, interested and motivated to maintain access. Further I have experienced that doctors prefers to be interviewed while they work (out patient clinical encounters or confirming of reports), while the others are more “flexible”.

3.4.2 Observations

Several researchers (for example Silverman 2001:287,288, Bratteteig 2003) have noted that there are often a difference between what people do, and what they say they do. That is, there

⁶ The names are pseudonyms

are differences between formal work descriptions and routines and what people actually do in order to get the work done (Bratteteig 2003, Orr 1996). Observations are thus important to identify the actual, instead of or in addition to, the spoken practice. The identification of the actual practice can then be used in order to create questions for interview sessions. Observation can thus be a technique which enables an introduction to the field: the how. How are the nurses, secretaries or others, working? Then the interview session can imply the why: why are you doing this? Why are you doing that? I initiated my fieldwork performing several observations. The observations were done in order to identify interesting topics which could be further elaborated, to understand how doctors, administration (secretaries) and nurses work individually and collectively on the patient treatment (discussing, negotiating, deciding); how they use Information Technology in their work; and how the interaction with the patients is carried out and forms the treatment process. Observations enables looking into “how things are” an ordinary work day. My observations were performed both in the out patient clinic meetings between doctors and patients; at the Post operation section were nurses work (write reports, take care of incoming patients, receive information, negotiate and discuss with doctors in daily morning meetings), and at the intake office were secretaries receive applications from the “external world”, where they identify and negotiate between resources, and have conversations with doctors as they perform some of their IT work. These observations enable a “richer” view of the interactions, the complexity and the actions carried out by individuals and between different individuals in order to make the best result out of available resources. The observation in the out patient clinical meetings enabled an understanding of what the different actors emphasize in interaction with one another (patient/parents – doctor), and how the treatment process is affected or decided upon through discussions and negotiations. The observation at the post enabled an understanding of the continually dynamic interaction between nurses within their own community, between nurses and other (doctors, secretaries) across communities. The same can be said about the intake office, as it is a “melting pot” between different communities (doctors, secretaries, different secretaries) performing their job through internal and external communication and negotiation. The observations at these settings established a core understanding of several phenomena, which were further explored using interviews.

Limitations

More direct observation of doctor work and patient-doctor interaction could have been performed, both in order to establish a more elaborative understanding of these matters, but also to be able to establish more profound and precise questions. The constraints of time can partly be blamed for this. Both time constraints regarding work with master thesis and time constraints for the professional workers. The first relates to the empirical theoretical “nature” of my thesis, and the necessity to delimit the scope in order to manage.

3.4.3 Researcher aspects

Walsham (1995) outlines two different roles in relation to interpretive research in IS: the outside observer and the involved researcher. In my fieldwork I was an outside observer who consulted the research area in some occasions to perform observations and interviews. There are some drawbacks as well as some advantages with this role, compared to the more involved role. I was of course seen as an outsider, and did just frequently appear in the setting. It is also more difficult, when performing this role, to uncover elaborately institutional tendencies, and in these matters the involved researcher role could be more appropriate. The advantages are the possibility that the subjects or informers may see the situation as less threatening and thereby provide information to the researcher in a freer way. This of course implies that the researcher has clarified his or her role in the situation. Initially I talked to the head of the department and used the opportunity to clarify my role. I brought with me schemes which emphasized the ethical aspects of the fieldwork, which defined how I would describe the information obtained by using pseudonyms; behave in a humble way towards workers and patients use discretion and formation. Another important thing for me to emphasize was that I was not there as an IT researcher first and foremost, but rather that I was interested in the way they worked, used IT to fulfil or accomplish work tasks, and to negotiate with others. I was then interested in both the organizational and the technological routines. Especially in the interactions with the patients or parents I was very focused on being careful. The diseases which I looked into have psychological impact on the parents, and I tried to arrange questions while being cautious. I did this by being very careful initially, asking general questions. As the interview/discussion went along I found

out what I could or could not ask them about. This because some of the parents were willing to talk about the disease and the conversation just floated, while others were more prudent.

3.4.4 Data analysis

The data analysis was inspired by Klein and Myers (1999) hermeneutical circle. I will here briefly outline their seven principles, before relating them to perspectives in my own work

The general principle of the hermeneutic circle is about moving between parts or fragments in separate communications, and which context the fragments occurred in. 'The process of interpretation moves from a precursory understanding of the parts to the whole and from a global understanding of the whole context back to an improved understanding of each part, i.e., the meanings of the words' (ibid: 71). The principle of contextualisation entails a reflection of the 'social and historical background of the research setting' (ibid: 72), the third principle is about the social construction of material through the interaction between researchers and participants. Further the principle of abstraction and generalization is about relating principle one and two (hermeneutic circle, contextualisation) to general concepts describing social action. The principle of dialogical reasoning refers to the preconceptions, assumptions; the researcher is confronted with throughout the process. The sixth principle of multiple interpretations describes how different actors view the same sequence or phenomena differently, and finally the seventh about having suspicion towards claims and biases performed by subjects (ibid)

Klein and Myers argue that these principles, led by the main principle of the hermeneutic circle, are about 'deciding on what relevant context(s) should be explored (principle two). This depends upon how the researcher "creates data" in interaction with the subjects (principle three) and the theory or concepts to which the researcher will be abstracting and generalizing (principle four). The researcher's own intellectual history (principle five), the different versions of "the story" the research unearths (principle six) is also important elements. Lastly the aspects of the "reality presented" that he or she questions critically (principle seven) deeply conditions the outcome of a research process.

In my analysis, all these principles are to some extent tried used. The first one is used to continually review the information in the light of new knowledge. This new knowledge is based on interaction with subjects and the creation of data in these interactions; this information is then seen through the lens of theories and concepts (actor-network theory and knowledge definitions); while reflecting on my own role (as outside observer), and multiple interpretations of the same phenomena (from different subjects). All this is critically questioned. Of special importance are the multiple interpretations. These interpretations can be seen in the light of the perspectives from different actors within communities or across communities. While some doctors may have a strong unwillingness towards the Internet, other doctors may emphasize its positive effects. More important may be the understanding of different conflicting interests among actors across communities, for example between doctors and patients/parents in the meetings. The multiple interpretations of the situation can sometimes create interferences which have to be dealt with. I will get back to this in the following chapters. Another important issue I focused a lot on is the principle of the hermeneutical circle. When I, as a researcher without experience, enter into a field, my knowledge will soon be reviewed in the light of new knowledge (I have already briefly talked about this in section 3.1.2.).

In the next chapter we will see the findings from the research approach discussed above. The fundamental question is to demonstrate how hospital professionals create, use and distribute knowledge, and how technological artefacts are used in this activity. Further the interactions between hospital professionals and the patients are described as an enactment where both the doctors and the patients and parents interests are taken into account.

EMPIRICAL CHAPTER

This chapter contains findings from my field work. Table 7 shows the general structure of the chapter. First I will briefly introduce aspects related to the disease I have looked at, before I describe the way from the disease is uncovered, via the general practitioner and the local hospital, to the expert hospital where the disease shall be treated. Section 4.3 is a description of working tasks and practices of the three groups or communities I observed and interviewed: secretaries, nurses and doctors. Section 4.4 is concentrated on giving initial aspects of patient focuses, before I in section 4.5 turn to the second core element, namely how patients interact with the professional workers. Finally a summary is given.

Section	What	Comment
4.1	Briefly about the disease and the patients	Introductory
4.2	Description of the treatment process	Introductory
4.3	Working tasks and practices amongst professionals	Core
4.4	Patient aspects	Background to section 5
4.5	Interaction between professionals and patients	Core

Table 7 : Overview empirical chapter

We can thus say that part 1 and 2 are introductory, and section 3 is the first core element. The section is about relating the different actor's knowledges to the implication it has on the patient treatment process, i.e., when they get involved, what they do when they get involved, which other actors they call upon, and how these negotiations and discussions fit the overall picture. This also implies how professionals use Information Technology to perform their working tasks. The different communities (physicians, nurses, others) have their own specific culture, aspects and focuses which shapes their knowledges. These perspectives are often obtained, used, and distributed within their specific community. Technology is an important mediator between different steps and between different workers in the treatment process. The second core element

is section 4.4 (background to section 4.5) and especially section 4.5 where I will focus on the interaction between doctors and patients, and how the different actors' interests shape the treatment process. I will focus on the importance of the patients' and parents' knowledges, and how they use the knowledge to shape the treatment process. The interaction shapes the decisions, and I am especially interested in the parents' participation in this. The interests of the different actors have to be aligned in order to create a successful the treatment process.

Figure 2 shows the general structure of this process or trajectory. The figure also indicate what my unit of analysis is, namely the expert hospital. The General Practitioner and the local hospital are thus only briefly mentioned in this thesis. I will talk more about this in section 4.2 in this chapter.

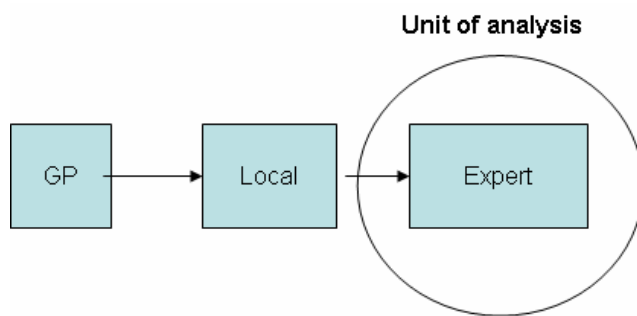


Figure 2 : The treatment process

4.1 The disease and the patients

The patients I look at have either craniosynostosis or brain tumours. I will briefly introduce the first disease here. Craniosynostosis is known as the premature closing of one or more of the bony gaps in an infant's skull. These gaps are known as the cranial sutures. In a normal infant not affected with craniosynostosis these sutures remain open throughout the first two year of life to allow for proper growth of the brain. The skull shape is affected by craniosynostosis according to which suture closes. Craniosynostosis is known to happen in about one in every 1500 births. The only treatment for Craniosynostosis is surgery. However, as further research is done, more surgical options are becoming available. Intracranial pressure and learning delays can be a few of the complications associated with uncorrected Craniosynostosis. A few other concerns are eyesight

problems, hearing delays, speech and mouth problems, and hydrocephalous (an abnormal collection of fluid in the brain which can lead to pressure if left untreated), to name a few. If Craniosynostosis is suspected the advice of a specialist should be sought out and a CAT scan should be performed. An X-Ray can not rule out Craniosynostosis and should always be followed with a CAT scan. (Harper 2004)

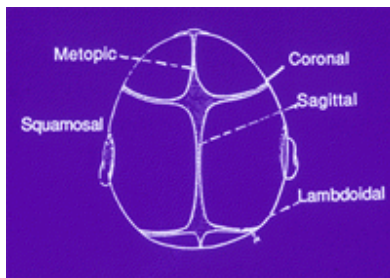


Figure 3 : Craniosynostosis (Source: PCS 2005)

The patients who have this disease are then children. They are in contact with health personnel in order to determine if they have to be operated, in order for the doctor to detect and assign necessary resources to their treatment process, to be operated, and to be treated afterwards. Because the patients are children, their “will” is often taken care of by their parents. This means that the hospital professionals have to deal with two clients. In addition this creates a situation where it is the parents who decide on behalf of the children. The psychosocial complexity related to this is not elaborative discussed in this thesis.

4.2 The treatment process

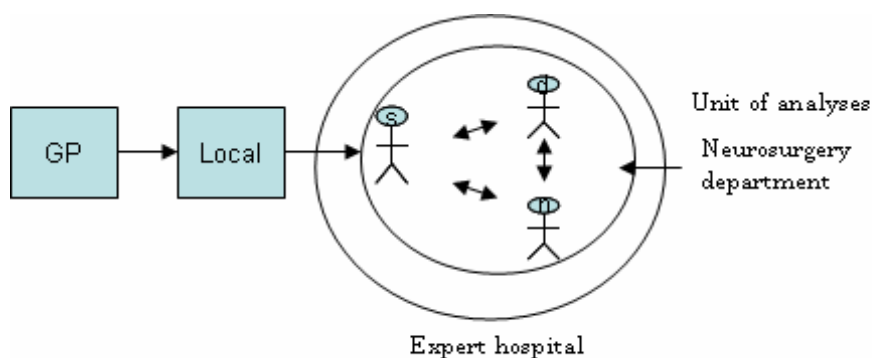


Figure 4 : The process and the unit of analysis

Figure 4, an “elaboration” of figure 2, shows the main human actors I have looked at within the expert hospital. The secretaries (s), the doctors (d) and the nurses (n) interact by performing negotiations often mediated and facilitated by technology. An application from the local hospital regarding a specific patient is received by secretaries at the expert hospital. The application is sent by mail. Internally the secretaries register patient information, locate and attach resources needed in order to continue the treatment process. This is done by calling upon other secretaries, and consulting doctors. The doctors identify possible time for appointment, and inform back to the secretaries. The secretaries send mail to the patients regarding time agreed upon. The patients have the possibilities to ask for changed schedule. The nurses are basically called into action with the arrival of the patient at the hospital later on. This chapter is basically about first telling the story of the internal negotiations both regarding registration and treatment, and secondly it describes the interaction between the internal professionals and the external lay people.

The process of discovering and curing the diseases I have studied, often starts within families, as it is often the mother who first notices and feels that something is wrong⁷. The process then consists of talking to the General Practitioner (GP), which transfers them to the Local Hospital which again engages expert help at expert institutions. The “road” or “trajectory” is much more inert and difficult than it may seem for an outsider. The GP has often relatively little knowledge of the disease, and is then only a bureaucratic referral point, which has to be engaged before one continues to the local hospital. This hospital may or may not have knowledge about the disease, but their participation is often about giving information on the disease, sometimes referring them to other patients who have been in similar situations earlier, but especially to put them on the track towards for example Rikshospitalet⁸. Rikshospitalet is an expert hospital where specialist physicians, like surgeons work. This means that Rikshospitalet is often used for complex occasions, or particular rare diseases or sufferings that few other hospitals treat. This means that getting appointments, operations, and follow-up will take time. The patient treatment process, as described here, means the way from a disease is “discovered” until the treatment is finished. This could take one year (often more) to all life.

⁷ There is a disagreement between the doctors I talked to regarding this. One (informer) says that it is often the mother who discovers that something is wrong, while another (e-mail question) says that this is not correct.

⁸ In Norway there are five neurosurgical departments: in Bergen, in Oslo (two departments) Trondheim and Tromsø

The rest of this chapter is structured as follows: Section 4.3 and 4.4 describes how secretaries, nurses and doctors works and use technology. It also talks about how lay people use Internet to get information related to the disease. Further section 4.5 contains empirical findings regarding how professionals and lay people interact. This includes four vignettes which demonstrate how lay people's interests are taken into account in the patient treatment process.

4.3 Working tasks and practices

After initially having introduced the disease and the patient group investigated in my fieldwork and further outlined the main aspects of the treatment process, I will now turn to the working tasks of different actors. The secretaries, nurse and doctors have different working tasks to perform in order to treat a patient as good as possible. The aim of the following section is to describe the working tasks of nurses, secretaries and doctors in order to better understand their main tasks and focuses. This enables a view of these groups knowledge work.

4.3.1 Secretaries

The administration consists of different type of workers, for example secretaries who perform several working tasks. Basically there are five main working tasks I have looked at: **First** secretaries extend the patient trajectories, meaning that they organize resources for income-treatment-outcome; **secondly** they produce writings, that is, write up reports given to them by doctors or others; **thirdly** they take care of, and distribute, incoming questions from patients or relatives regarding routines, sufferings etc, **fourthly** they organize out-of-schedule encounters , and **finally**; they are important providers of structure when implementing new routines

Extend patient treatment process and negotiate between resources

The task of registering the patient and attaching information to the specific patient process, consists of receiving application from external hospitals, identify resources internally, and then notify patients when proper resources are found, registered and coordinated (by the patient coordinator). This is not an easy task, as it contains many different possible outcomes, and it

includes using a number of different artefacts from paper to post-it notes, from Information Technology to telephones. We can see that it is a complex heterogeneous network where subjects like human beings and objects like artefacts together perform action.

With the application note, from the external hospital (referral letter), there should be x-ray images of the patient and the disease (for example the tumour or the sutures in the head). These are usually sent by mail, but they are often lacking as well. Then the secretaries have to remind and nag on the local hospital and general practitioner to get them. Sometimes they do not even know which institution that produced the x-rays. In these situations they use their knowledge about where different x-ray institutions are situated, contacting those ones in order to trace the x-rays. When the x-ray images are received at Rikshospitalet, there is a need for additional detailed images which have to be taken at Rikshospitalet; the expert doctor (surgeon) needs them to decide exactly what to do during the operation. The activity of taking these images is performed by a third actor, an external or internal x-ray institute, and it has to be ordered in advance

The referral letter is scanned into the Patient Information System (PIMS), which is connected with the Folkeregisteret, and additional information on the patient is looked up (often through docuLive which is linked up from PIMS). If the newest information (in the Patient Record) is so old (before 2000) that it is not scanned yet, the secretaries have to order the paper record from the archive department. These records arrive the following day, when a person from the archive delivers them.

The point is to structure the information in a way that makes it easy for the patient-coordinator and the doctors to continue the processing of the application. The referral letters are distributed to the most “suitable” doctor (a categorization of doctor qualities is mentioned in section 4.3.3) in relation to the actual disease. This is done by putting the referral letter onto shelves from where doctors pick them up. The secretaries thus have to identify, locate and negotiate between different resources, both “internally” (in the neurosurgery department) and externally (different resources in other departments at Rikshospitalet or other institutions outside Rikshospitalet). The doctors receive the information on registered patients (from the secretaries), and decide when they shall be operated, based on decisions regarding the urgency of the disease. The patient coordinator

uses a computer program to find possible time slots in the period indicated by the doctor, and communicates (often orally or written on a note) to the secretaries the available time. This temporarily decided schedule is then registered into PIMS, by the secretaries. The schedules is temporarily and flexible in order to deal with possible deviations. The schedules are agreed upon at fixed meetings, were doctors, nurses and administration workers discussing the existing schedules. This meeting is performed once a week. (O3-130605, Steinvik 2004: 27-28, and 43, 44)

The information about the patient is then accessible from within the Electronic Patient Record for anyone who has the legitimacy to access. The different actors are thereafter obliged to update this “patient history” information whenever it is modified or additional information is added. This may be information regarding daily consultations during the hospital stay, regular or additional consultations or follow up after treatment, or historical paper-based information scanned in afterwards.

When the secretaries negotiate with the doctors on finding a suitable time, flatter can be a good technique. An example is the secretary who first sent an e-mail to a doctor, and then asked him when he was working at the intake office:

Secretary: “Is it ok for you to perform the out patient clinic in June then?”

Doctor: “Yes, I can do it in week 26, only because you flattered me in the mail”

Secretary: “That is nice, many patients will be happy know” (this is in the summer months and little resources are available, the doctor worked extra doing this work)

To sum up, the secretaries have to negotiate and communicate with different actors in order to attach the resources needed to treat the patient and in this way extending ⁹the patient trajectory

Produce writing

⁹ By extend here I do not mean waste time, or loose time, but rather extending as a bridging effect: the secretaries makes a bridge between possibly needed and available resources, so the treatment process can continue.

The secretaries are also producers of official or internal reports based on patient treatments. In other words they are some of the producers of the written information regarding the patient treatment process. In total the secretaries write around 30 different reports (MA-J-03012006). Examples of such reports are the out-patient clinic notes from the doctor, read in from Dicom. The doctors read information regarding decisions and agreements with patients or parents obtained during the out-patient clinic consultation. These readings are then written by the secretaries into DocuLive, and are afterwards to be signed by the expert doctor. In-between the consultations or treatments at the expert hospital, patients and parents sometimes have meetings with doctors at the local hospital, or with the general practitioner. These external doctors then request the reports written at the expert hospital, in order to inform the patients of the process. If the expert doctor has not signed the report internally in the expert hospital, the secretaries have to decide whether they can send it out of the institution or not. Due to the reports' importance they often send it anyway and the information is transferred even though it has not been officially approved. (MA-J-270405)

The secretaries have to be precise when they write discharge letters and other reports. They learn from each other, read books, and inform each other. This is especially done in everyday interactions, in meetings and in lunch breaks. There is a tendency of outsourcing these services in western hospitals, and some of the secretaries say that this is not an ideal thing:

Persons who are not accustomed to writing using medical terminologies often tend to be imprecise. Examples are doctors who tend to use medical language and "difficult" formulations; in addition they sometimes forget codes and other factors. During the evening and night the emergency unit registers incoming telephone calls. The emergency unit also sometimes writes things which later have to be interpreted by us (the secretaries). It is then very important to have translators who can relatively quickly understand what is wrong, and how it shall be corrected. The outsourcing of these services has shown that it sometimes is necessary to have a "controller" who can check what has been written, and if so the value of outsourcing is sometimes lost.

(I-G-051205)

We can then see that the secretaries writing imply an understanding of technicalities and specifications regarding the formulations in reports. We can also look at the secretaries claims as done in order to “protect” her job as a secretary. The tendency of outsourcing writing services is by all means present in western hospitals.

Organize out-of-schedule encounters and take care of incoming questions

Some of the patients may have in-operated equipment, which has to be adjusted in the body. This could be Parkinson patients with stimulators where the battery is flat. These activities are then quick to fix, but important to fix in a hurry. It is the secretaries’ job to organize the quick-fix of these trivial but important matters. These types of scheduling demand quick treatment, and the needed resources (doctors, treatment time) must be quickly attached in order to perform in a hurry. (O3-10605)

The doctors are often very good at encouraging the parents to write questions when they are away from the hospital. They are not that good in responding when the actual enquiry arrives. The job is then for the secretaries and administration personnel to convey the question from the patients to the doctors. This implies asking the parents to structure and prepare the questions in a manner that facilitates the response from the doctor. (O3-10605)

Providing structure and efficiency

The Office executive has the responsibility for all the secretaries and office personnel working in the neurosurgery department, 27 persons in total. This means that she has to be an active part in negotiating, discussing report standards before they are implemented, and check that they are followed during daily production. During the diffusion of the portal, she had a very important role in creating structures for how to implement, how to use the new Information Technology, and how to support the users when problems occurred. They created a system where one-to-one learning was used. This meant that a person who knew how to use the EPR learned another who did not know. In addition they had to create a system forcing the doctors to use the electronic journal. The Office executive says that “the doctors thought they could just order the paper

journal as before”, and that “doctors did not show up at the courses arranged by us and the IT department” (I-081105). They had to force the doctors from day one, and this was done by sending one of the persons who knew how to register in the EPR to train the doctor immediately after the doctor complained. Other departments have had enormous difficulties in this transition from papers to CSAM, and the office executive thinks that the strategy they chose helped them avoid similar difficulties. The secretaries were in these matters used to teach others how to use the IT, and to take care of problems individual workers encountered during their work. They had to perform ad-hoc in order to keep the treatment process going.

(I-081105)

I have now outlined some of the main aspects of the secretaries’ work at the neurosurgery department at Rikshospitalet. Further I will in the same way describe the nurses’ tasks at the same department

4.3.2 Nurses

In this section I will first describe the working area where the nurses are positioned, briefly mention the equipment which they use, and some of the activities going on at the working place. Further I will turn to aspects which relates to their working tasks, and overall philosophy or principles of nursing. This regards amongst other things how nursing aspects are tried implemented in digital frameworks like the EPR. Finally a description of some aspects of their work regarding the “culture” within their community is given. The section has as its point to describe nurses as human actors who has an important role in performing both care and cure. This also implies how nursing factors is inscribed into EPR standard reports

Working area

The nurses at the neurosurgery department are mainly positioned in or around the post operation section. In this post section there is a working unit and a patient preserving unit. The main activities here are:

- Doctors and nurses discuss the patients in the morning meeting

- Nurses use it as a working room for writing notes, formal and informal schemes and forms, and phoning patients or parents.
- Nurses discussing and talking while they wait for patients who arrive or tasks from doctors or others

The room is equipped with 7 pc screens, and one big screen. The big screen is being used while discussing patients in the morning meeting. The room has a big table in the middle and some chairs.

The patient units have three different patient rooms but also social rooms, where parents can meet other parents, nurses and secretaries. The three patient rooms in this section are organized according to the patient's condition. Some of the patients are positioned in the "surveillance" room (just finished operation), some of them on the outside (ready for operation or finished operation) and some in the isolate (infections that are dangerous).

The surveillance room for just children just operated, has several pc, amongst them several which monitor different curves regarding the patient. These screens are called "scoops", and are used for displaying pulse, oxygen saturation in the blood, blood pressure and heartbeats (if wanted). One can also use them for measuring ICP (intracranial pressure), arterial pressure, and venous pressure. (O2-300405)

Working tasks

The nurses have several working tasks during a normal day. We can categorize them in two parts; the caring and checking up on patients, and the writing which includes structuring and writing of several (more or less) standardized reports.

The **caring** for patients are not a defined structured task, but one that arises any time a patient needs attention. The nurses define this "caring-factor" as their number ONE task; the caring and nurturing of patients are the basic motivation behind nursing work.

The second main task relates to **writing of reports**. These are reports that regard the patient treatment process and are used in order to observe the evolution of the patient's health during the hospital stay. Examples of such reports are: Vaktrapport, sykepleierinnkomst, sammendrag and sykepleiersammenfatning. All these reports have a "nursing focus" implemented in them, that is, they focus on both cure (physical treatment of the patient) and care (psychosocial focus which enhances caring factors)

Structuring care and environment

The nurses are important actors in accommodating new technology to the network. The introduction of new technology in the organisation carries with it the change of standards, structures and routines. These are not necessarily fundamental changes, but changes there are all the same. Standards related to these reports (when they passed from paper information registering to digital information registering in docuLive) were developed by a VIPS¹⁰ group (a group for discussion models and structures at the section). The VIPS model is a structured model for nurse documentation. The VIPS group consist of several different employees', and do also include nurses from several departments, amongst them nurses from the "floor" (as the nurse puts it) (MA-I-040505). The nursing reports are thus negotiated between different actors, both nurses and others. There are however technological constraints, as well as standards that have to be accommodated to the possibilities that there is in the docuLive system (O2-300405). The impact is then both from the standardization organs, from the nursing practice, and from limitations or possibilities in the technological system. The structure of this report does however enable the nurses to explicitly state the physical as well as more psycho-social conditions of the patients. It enables the combination of cure and care in an explicit manner.

Nurses also have an important impact on the institutional forming of the departments where they work. They enable a freer atmosphere by serving food from the bakery, making jokes and having fun. This atmosphere is very liberating in relation to the serious and often sorrowful tasks they

¹⁰ The VIPS group is an internal compound group at the neurosurgery. It consists of professional and research personnel, some 'undervisningssykepleiere' (at the children and mature post) and in addition some nurses from 'the floor'

are to perform. While observing and interviewing the nurses I could see doctors coming in, sitting down and chat with them, and sit there for a while, instead of going to their offices.

The next section includes examples of statements from a report based on VIPS standards

Elements of care in standards

The nurses are in many ways subjects that make life, sustainable for the patients and the parents when they are forced to spend time at the clinic. They try to be well prepared when the patients arrive, provide them with information, helpful but honest, and nurse them through this rather difficult period. Some of the parents I talked to were very grateful and impressed by the nurses at the Post saying for example that: “The nurses at the Post were very sweet and nice” (I-P1-221105). The nurses are themselves very engaged in this caring-factor:

“The most important thing for us is to attend the children and the parents’ needs. Our issue is to calm them, give them medications (if needed), relieve, and make children and their parents feel safe”

“I try to focus on the individual needs that the patients have. This includes trying to identify their mental situation in advance, and provide comfort”
(I-041105)

Sometimes children are born with “defects” without the parents knowing in advance. Imagine the joy and excitement related to the birth of an heiress, and the big disappointment when the child has sufferings that can follow him/her through the entire life, and thus radically changes the family life. The nurses are extremely important care-takers, as they deal with disappointment, apathy, sometimes even shock. When children are born with bone marrow hernia there could be serious damages to the nervous system causing from light to heavy paralysis on the patient. It is then very important to feed the child with the mother’s milk as it contains alimentary and anti material which can make the child stronger:

”I have tried to explain mom that it is very important that she pumps her breasts regularly to avoid breast pressure and loss of milk. It is important to repeat this information to mom”

“Mom and dad have been very sad today. I have tried to talk to mom about the positive things with the baby, and try to understand her sadness in this. I have said to dad that he must not hesitate if there is something he would like to talk about, we are here for them and their children”

(MA-I-051005)

I emphasize the tone in the sentences. She does not say the mother or the father, she says mom and dad. It is a much “closer” and “intimate” way to express it. And this is not expressed orally, but in fact written in the documents, signalling the importance to balance professionalism and intimacy in these somewhat standardized reports.

The nurses are not only human actors who focus on care, but also translators of information given by the doctor. The doctors are sometimes using a difficult language when talking to patients, and it is the nurse’s task to translate this into understandable information:

”The doctors sometimes use difficult language and then we have to explain expressions in a more understandable way to the parents”

Distribution of work within group

The nurses are constrained by time and the amount of patients that need to be treated. It is therefore sometimes difficult to give the needed attention to every patient

”It is important that we spend a lot of time with the patient, and that our time constraint is not visible for them. This is a mundane task we learn along the way, to distribute and delegate tasks between us” (I-4.5-041005)

It is also sometimes difficult for the nurses to understand the shock and stress parents experience when their child is suffering

“When we focus on the daily treatment, the parents/patients are already a long way into future possible hypotheses. They are not able to understand the small steps, and here the portioning of information is very important.”

(I-4.5-041005)

A hospital is often influenced by time pressure, short schedules and busy doctors. This makes an impact on the nurses, as they sometimes try to “hide” pressure and stress from the patients

“It is important to know what is possible to delegate and what is not. One could easily be looked at as lazy by other nurses, and there are nurses that it is more difficult to take tasks from, than others. There are some that we easily see through” (I-4.5-041005)

This indicates that there is a coherent group culture, working tasks can easily be distributed amongst the nurses but only if everyone participates in making the group a strong unit, where everyone trusts and works hard for each other. I interviewed two nurses at the same time and in this part of the discussion it was the most experienced who talked. Obviously there is a culture where one is supposed to perform first and talk later.

Interact with doctors

In the morning meetings the nurses and the doctors discuss the conditions of the patient, the progress/lack of progress, what has taken place and what should be done. These are meetings where nurses provide information about physical and to some extent psycho-social aspects on how the patient is behaving, and where the doctors relate this to their own knowledge and decide what to do. The EPR is here used as an information tool and a scientific medium like x-rays are an important part of the session. The information is displayed on big screens and discussed. Decisions are taken.

In summary we can say that nurses can be seen as subjects or human actors who focus on both cure and care. Cure in the sense that they are important “extensions” of the doctor both when explaining diseases, in translating difficult medical terms into “understandable” (for the patient) language, and when focusing on the physical conditions of the patients. They are however important human care takers as well, as they implement nursing report standards that include focus on taking care of the psychosocial aspects of patient treatment as well. A problem may be that they sometimes become “normalised” workers who have problems in giving the patients the individual follow-up they sometimes need.

4.3.3 Doctors

So far I have described working tasks and other aspects of secretary and nursing work and how different artefacts is used in the activity of communication and distribution of knowledge. These artefacts can be equipment like telephones, pens or papers, and also different types of Information Technology. We can see that this creates a heterogeneous network where subjects and objects are “partners” who together perform action.

In this section I will briefly describe doctors’ work at the neurosurgery department. This is done in order to give an understanding of some general activities the doctor has, and in order to indicate that there are different types of patients, at different levels of the treatment process. The issue is to briefly describe doctors’ work, and general activities performed by doctors at the neurosurgery department, as a background for discussing interactions later

The doctors at the Neurosurgery department have several working areas and these includes for example epilepsy and spastically suffering, tumour and cysts, Parkinson tremor, Neck-back sufferings, vascular sufferings, hydrocephalus, cranium synostosis. The patients I am concerned with are mainly within the area of synostosis and tumours

The interaction I observed was basically at out patient clinical meetings between patients, parents and doctors. The out patient clinic can be used to identify patients who need operation; it is a

forum for checking up regularly on patients operated for synostosis the first three years of their lives (the data from the patients evolution is used for research); and to check up on patients where chirurgical interventions already have been performed, but who have chronic implications as a consequence of their disease. The doctor uses the EPR to read information about the patient, and this implies both written information regarding the history of the treatment process, but especially the x-ray images accessed within the PACS system¹¹. The doctor tries to interpret the information and look for deviances, changes or other things which are important regarding the disease. The PACS images are especially important information on the synostosis patients as it shows what type of suture closure¹² the patient has. In addition to different types of synostosis there are of course different degrees of suffering. Sometimes the patient is only partly affected and operation is not necessary. After the out patient clinic consultations the doctors use the dicom system in order to dictate a report. The system is a communication tool between doctor and secretary, the doctor reads, the secretary writes. The writing part done by the secretary was mentioned in section 4.3.1. The doctor I observed read in the information clearly and carefully, and used certain codes in order to describe aspects related to the disease. The readings are based on a summary of the treatment history, and the new information obtained during the last encounter. After a while, when the secretary has written the dictate into docuLive, it is returned to the doctor through the EPR system. The doctor thereafter confirms the note with a digital signature. This process of reading and confirming is something the doctor would like to do in-between encounters, operations or other activities. Therefore there are some computers available for the doctors to use at different offices in the department. The doctor can thus access “knowledge”, i.e. information on the patient interpreted and used by the doctor, from anywhere in the department.

As earlier mentioned, the patients are at different stages in the treatment process: there are the **non-operated**; the operated who are doing well but has to be followed for three years by routine, “**routine-check**” patients; and the operated with **chronic** implications. The doctor is an important resource in the negotiations and discussions which creates a fundament for decision regarding the patients in all these phases.

¹¹ PACS is an electronic system for storing and showing of radiological pictures, both x-ray images, ultrasound, CT and MR scanning (<http://www.rikshospitalet.no/view/readnews.asp?nPubID=647>)

¹² There can be at least 5 different types of synostosis: lambdaidea, saggital, bicoronal, metopica, unicoronal http://www.sahlgrenska.se/upload/SU/omrade_oss/plastik/kraniobroschyren.pdf (see also figure 3)

Examples of **non-operated** patients are patients where the doctor suspect premature enclosure of suture or a tumour located in the brain. The out patient clinic is in these matters used for locating patients where operation is a possibility. Decisions are made by discussions between doctors and patients or parents, while reflecting on how the disease has evolved from being suspected and during the first year of the child. The decisions are taken using information from external hospital, x-rays picture from local hospital and special x-rays taken later, in addition to discussions with patients.

After the child is operated, it is necessary to perform follow up for several years afterwards. The “**routine-check**” period is normally three years, and patients who have not encountered problems after operation and three years in advance, will be considered cured. When patients encounter problems during these three years, regarding the growth of the skeleton, they may be “transferred” to the “chronic” group, and followed up several years to come.

Patients who encounter problem will then be regarded as **chronic** patients, and further surgery, operations and consultancy might have to take place. The patient who has chronic implications related to synostosis often suffers from synostosis syndrome. Synostosis syndrome is a congenital suffering in contrast to ordinary synostosis. The patients with syndrome therefore have to be treated more regularly and often until they reach the age of 20 years. The treatments for these patients can be smaller operations like the replacement of the tube which drains liquid from, or provides liquid to the brain, or it can be bigger operations caused by problems with the skeleton occurred during growth. The head normally develops till the age of 20 years. The doctor at the neurosurgical is in some of these cases a provider of advice regarding the specific problem, and which type of expert should be contacted (orthopaedist, dentist). Information used for deciding which steps to be taken implies consulting x-ray pictures, discussing with patients, reflecting on own experience.

The importance of sharing

In order to have a motivated and inspired working environment sharing of knowledge and experience has to be stimulated within as well as between communities. At least one of the doctors is in addition an important “activator” of sources and resources in the network. As the administration person put it:

”the doctor is one of the most skilful, and he delegates and activates people. He cooperates and is charismatic; he selects and uses the one who matches him. I have given him and a secretary freedom to work flexible and this works well, he stops by my office everyday and reports how things are”

I had earlier noticed secretaries complaining about that this actual doctor were not very “structured” and that he was received special treatment regarding writing support etc from others. I therefore asked: why does he then need special treatment?

”Because he is the most-working doctor (there is statistic on this within docuLive, that is, the number of dicoms within specific periods). He engages and motivates other people, in contrast to others who sit in their offices and do not share...he is innovative and updated, he keeps himself informed. When he is interested in something it accelerates. An example of this is the craniofacial team. The activity accelerated when he started working on it. Although it had existed for some time, the progress was very slow, but he changed that”
(I-081105)

This emphasises the importance of sharing, being active, motivate and distribute and delegate tasks within the department, in order to stimulate quantitative and qualitative “production”. However it also indicates that production and efficiency is an important perspective.

I have now briefly described the doctor’s work regarding decisions on which steps should be taken in order to treat the patient. I have also briefly mentioned how technology is used in these matters. I will now turn to patients, and briefly outline which group of patients I have interviewed and observed, what their suffering is, and how they tries to obtain information.

4.4 Patients

The parents I interviewed all had children who suffered from synostosis, with one exception. I found it interesting to interview a woman who had been treated outside Rikshospitalet. By interviewing here I accomplished the following: I was able to hear perspectives from a someone who was old enough not to be dependent on her parents and thus see a more doctor-patient relationship (without the interference of parents in-between); it enabled me to talk to a person who had had something else than synostosis, namely tumour, still remaining within the area of neurosurgery; and finally it gave me the possibility to talk with a patient who had been treated elsewhere. The rest of the informers were parents, as it was small children who had the disease. The parents reacted differently to the message that their children had the disease, and there were also different degrees of help received from the health system. In some situations the initial levels like the general practitioners and the local hospital was of little help other than in transferring them to the expert hospital. Other times they were helpful and the process goes “smooth”. A general problem mentioned by the parents was the difficulties they encountered in getting helpful and trustful information both from the health professional and on the Internet, where the information was sometimes seen as frightening, or too medical. The parents have a basic need of information that can give them answers, that can make them trust the professionals, and which is important for them in order to maintain a relatively stable and secure family relationship during the treatment process. In section 4.5 I will describe aspects of interaction between professionals and lay people, but at the clinic, there are interactions between different families (lay people) as well. The nurses I talked to said that the social room they have at the department is often used by parents and patients when parents are visiting, or by parents whose child is recently operated. A problem which arises is that parents with more experience (their child is in the later stages of the treatment process), sometimes frighten the parents with more recent operated children: “they bring along scary information from Internet and frighten the less experienced” as a nurse put it.

More elements regarding the patients attitudes, moods, interests and behaviour is given in the next section

4.5 Interaction between professional communities and lay people

I have so far briefly described the disease and the treatment process, before I turned to describing working tasks and aspects related to the work of the professional secretaries, nurses and doctors. I also described the way other subjects (human actors) and objects (non human actors like technology) were called upon and used during the process of knowledge work within the hospital.

Further I will turn to the interaction between the professionals and the lay or lay people. First I will describe aspects related to how the professionals look at the lay people's main information medium, the Internet. Then I will describe the parents view Internet, and some comments related to their use of it. The most important part of this section is how the treatment process gathers different knowledge communities, and especially how the professional and lay people together interact in order to make a secure treatment process. This will be dealt with in section 4.5.2 and 4.5.3 below.

4.5.1 Doctors, nurses, secretaries and patients on Internet information

The Internet is a technological medium, partly unfiltered containing an extreme amount of information. The Internet may be seen as the lay or lay people's richest medium when we are talking about available information. In this part I will first give some responses from the health worker's on my questions regarding what they think about patient's use of Internet. Then I will turn to the patients and parents responses to the same issues. In this section I will thus outline how Internet is thought of by some of the health professionals I talked to, and how it is used by the parents and patients I interviewed

The Internet provides information to patients, doctors as well as everyone else. Historically the doctors have kept the information tight too their chest, and out of patients reach, and provided only oral versions of the disease to the patients. Now much medical information is available on the Internet. Some of the doctors are sceptical to this:

”We prefer to control the information; we are not enthusiastic about the information on the net. They read many strange things, and the information is not personalized to specific patients. I do not like the competition, and it leads us using a lot of time to reject many of the things the patients has read”

(I-D1-041005)

Some of the nurses are also sceptical to the use of Internet, and the information patients and relatives gain. This partly relates to fear that the patients are confused by the information.

“The use of Internet for information browsing can lead to fear and worry as well, because there is frightening propaganda there (O2-300405) and they find terrible things and get scared” (I-041005)

“they all want to know as much as possible. Many parents say that the information on the Internet gives them fear, and that they do not want to browse more. The information can however help them”

“The information [they read from Internet] can create fear, and is then negative. They read everything uncritically; they have read about mystical methods on the Internet and want us to use these techniques. The patients believe everything they read, and are very pushy towards us. They have for example read about mystical methods from Sweden”

Sweden differs from Norway regarding treatment methods?

“Yes, Sweden is more liberal when it comes to treatment techniques and uses methods our doctor says is not scientifically proven, we are more carefully in Norway. The patients have wished to get information from Sweden, but the doctor has refused this”(I-4.5 041005)

I asked a doctor about this: are there techniques in Sweden not used in Norway?

“There is a private institution in Sweden which has an idea regarding the use of feathers which can be placed in the open suture. It is not proved that this method is suitable though. In addition the feathers are not available commercially. The doctors in Sweden better try the methods out on the Swedes first, and then we will see what happens”
(I-051205)

Even though Internet can be discussable, for some patients it is a source of information that can relieve, comfort and inform:

“After we had received the official description of the disease, we looked it up on the Internet and this helped us understand the diagnosis”
(I-P1-221105)

Some of the workers admit that the information patients and parents sometimes found on the web can help them, and that the patients sometimes know more than the doctor:

“we have to explain our choices (regarding operation and treatment) all the time, and they sometimes know things we do not know ourselves. Sometimes it is embarrassing for the doctor as well”
(I-4.5-041005)

”Sometimes the patients and parents are very well-informed even more than their own doctor”
(I-J-081105)

The parents and patient’s use of Internet

The parents use Internet to a certain degree, some more than others. Some uses Internet to browse for general information about Rikshospitalet, while others use it profoundly to browse

information about the diseases, and also to communicate with others. This comes from both the statements from the nurses and the parents themselves. The nurses say that patients have read about several cases from USA and Sweden, and refer to these cases when arriving at the hospital. The parents use Internet both to find information on the disease, but also information regarding the entrance into a medical society, in other words general information about hospital, health, disease, and operations.

“Internet has given us useful information, although the American sites sometimes tend to include much medical information” and

“The pages are normally very informative, and makes us curious, although the pictures sometimes are a bit grotesque”

(I-P1-221105)

This gives an important distinction between different types of parents. Parents that are used to images of children with diseases, or who do not get frightened when seeing these pictures, tend to use Internet more frequently than the ones who easily get scared:

“all the horrible pictures on the Internet make me feel uncomfortable”

(I-P1-251005)

Some says that they tried to find information regarding the disease on Internet but that they did not find anything particular

We tried to search for information on Internet, but found little we could use. We used the Internet to identify general information regarding the hospital stay, how to behave, about the department where we spent time when the child was operated. We did also lookup information on narcosis, on the diagnostics and briefly about the fontanelles” (I-P2-251005)

The doctors are often eager to communicate information to patients, but have little time. The craniofacial team¹³ has created a web site, administrated by one of the secretaries in the team. She says that she is “on shaky ground” when designing web-sites, have little knowledge about it, but that it is important to get information out on the web. The information on the craniofacial site is of very limited use for the patients, and none of the patients I interviewed mentioned this web site when talking about Internet and information regarding their child’s suffering.

I will now turn to a core element in this chapter, namely aspects related to the interaction between the professionals and the lay people. First I will describe some introductory elements regarding the doctor – patient interaction, before I in four vignettes describe how patients perform in the interaction with the doctors. **The point** is to identify interests and elements of patient and parents performance which is used in their strategies, and see how these interests are dealt with by the doctor.

4.5.2 Doctors interaction with patients

Doctors have knowledge about detecting diseases, how to perform operation in order to fix the problem, and what to focus on in the period after operations. Doctors also do research in order to discover new diseases, and experiment using new operation equipment. This is a fundamental part of the expert doctor’s work. Basically my focus here will be on how doctors perform in interaction with the patient, what they focus on and how they use technology to update their own knowledge on a particular patient, and to register information afterwards.

When preparing for and performing out patient clinical meetings with the patients, the doctors use both paper information (prepared beforehand by a nurse) and the EPR to read and get updated about patients.

The doctor looks-up information in the EPR, read the historical process of the patient, and studies specifically the x-rays. The patient is followed in by a nurse, and the doctor spends

¹³ The Craniofacial team (www.craniofacial.no) is a team which consists of persons with different expertise’s all related to conditions provoked by craniofacial sufferings. This can be surgeons, dentists, nurses, face surgeons, eye-nose-ear experts, etc.

the time before the patient and parents arrival reading the journal. During the encounter he first asks general social questions, like how you are doing, is everything fine, before the questions become more disease related. The questions are related to the evolution of the disease, also regarding how the additional external treatments (like orthopaedic, eye doctor, odontology) are going. The patients with **synostosis syndrome** (mentioned earlier) might have in-operated shunts (a tube which helps the process of providing and removing liquid to the head). The shunt, which goes from the head to the stomach, sometimes tends to be blocked. This can create physical problems for the patient, and the parents are worried. The doctor, helped by the x-rays, can provide comfort in these matters, by saying that it looks fine. Some of the information received from the parents, for example increasing headache, is not visible on pictures, like x-rays. The doctors then have to use their knowledge, while taking into account the parents knowledge, in order to decide on what to do. If for example the child is growing, and the shunt has become too short, then operation is needed. The information the parents have on how the child is doing is therefore sometimes very important for the doctor. After the encounter the doctor reads in information in the dicom and prepares for the next patient (01-120405)

The doctor is seen as an important provider of security. The doctors are busy and there are few opportunities for the parents to meet them. One of the parents noted that ‘the consultation was not absolutely necessary, but they wanted it anyway, and the boy remembered the doctor, even after all the other doctors he has met during his life’.

In the more informal encounters between doctors and patients, like meetings at the Post or in the patient department, the doctor’s ability to give concrete and good information is mentioned:

“The doctors are very good at drawing sketches, showing the parents and the patients where the tumour or the suture is placed. They provide good concrete information portioned to the specific patient” (I-4.5-041005)

The doctors are also very focused on evidence, both from their own practice and from “objective” experiences learned from education, training, practice and conferences where they meet

participants from doctor communities. The doctors I talked to are not all that positive towards information parents and patients read on the Internet (see Internet section). “There is no evidence. There is just information and it does not relate to a specific case”. “We have to wait until the operation techniques and strategies have been confirmed or proven” and “The parents and patients do not have the ability to filter the information they read”. One of the doctors stresses that he is positive towards parents and patients who read information, it is a privilege they have. Another doctor says that he prefers controlling the information and that the information from Internet creates “noise”. Whether Internet shall be given the blame for this “noise” is not obvious, but the presence of “aggressive patients” can be regularly observed, as in this story:

I am sitting talking to a doctor, while he is confirming information written by secretaries (as we remember doctors read information into dicom, secretaries writes it into docuLive, doctors confirm the written information), he receives a phone call. It is the sister of a man with a tumour in his head. (I hear from what the doctor answers what she is talking about, and I asked him afterwards about some of the things they talked about). She says to the doctor that she has talked to a friend of her who is a doctor, and he said that it would be better to operate with gamma knives. The doctor protests and says that there is a common agreement on the necessity to first make an intervention, and then use ultra sound. The talk continues, the sister stresses her arguments; the doctor emphasizes his point of view. In the end he says that she is perfectly free to choose whatever institution she wants to perform operation. The conversation is over. Afterwards the doctor says a bit irritated, that Rikshospitalet has the best expertise regarding this type of operations. “You will not be operated better elsewhere”. (O3-10605)

Till now I have described some observations regarding the doctor’s interaction with patients. Further I will tell four stories about how the interests of the patients and the doctors arise, and how they are dealt with.

4.5.3 Patients and doctors: the interaction shapes the treatment process

This section is dedicated four vignettes which show how patients and parents introduce their different interests and how these are taken care of. This is done in order to investigate how professionals and lay people together perform the treatment process.

VIGNETTE 1

The patient is a two year old boy. The boy is not operated; he is what we can call a border issue where it is not yet decided if he should be operated or not. The boy and the mother are at Rikshospitalet today for further check. The doctor will talk to the mother and decide what to do next. Because of delays, out patient clinic meetings can sometimes be shorter than the scheduled 30 minutes. The doctor reads in the docuLive, and is especially interested in the reference letter from an external doctor, and the x-rays taken by the x-ray institution. The sutures have been closed a bit early, and the doctor has to decide, helped by the mother, if operation is needed. The x-ray does not clearly reveal if the boys head has changed or not. The mother and the patient arrive. The doctor says, after a short while, that he cannot see any changes on the patient. “This is nonsense” says the mom. “Everyone can see it”. The doctor then adjusts himself by taking up a tape measurer and measures the boys head saying: “with a closer look I can see the difference, but I did not see anything from the x-ray pictures”. But, he continues, there are no big problems, and the mother agrees. The doctor writes a requisition, and asks the mother to appoint the photo department for photography. The photo is placed in the journal, and can be used for research later on.

This vignette shows that parents not necessarily accept the doctor’s statements right away. They are eager to protest against what they conceive as error, and these “protests” can sometimes make the doctor adjust himself. The adjustment, caused by the parent interference, can sometimes create a better process from then on (O1-120405)

VIGNETTE 2

Sometimes parents have difficulties with the health system from early on and throughout the process. They have both the feeling of inadequacy, the feeling of sadness and stress during the treatment process. The disease was discovered by a doctor at the local hospital who ordered x-

rays to be taken. The GP did not know anything about the disease, but had heard of a similar case before, and set them in contact with this family. This family had experienced a very difficult process: they had been ignored early in the process, and had to “fight” with the health system in order to operate the child. The child was operated before suffering lasting damages, but only just. Their experience did not comfort “our” family:

“These parents where suppose to help and relieve us, but they only added to our discomfort in stressing that: you have to operate otherwise his brain will be damaged. This made us insecure.”

Two months after the child was born “our family” went to Rikshospitalet for control. The doctors at RH said that there was not hurry; the child would not get disease related problems (intracranial pressure) before he reached his first year of age. Despite the worrying messages from the other parents, they were calmed down by the conclusion from the expert doctors at RH. They did encounter problems however. The child started screaming when he was baptised some days after the Rikshospitalet encounter. They were summoned to Rikshospitalet: the child was to be operated (4 months after birth). The doctors had earlier said that there was not any hurry, but did anyway call them in for operation two months afterwards. The child’s suffering had increased considerably, and operation was necessary.

The parents did not get any follow-up between control (2 months) and the operation. They did not even know that the child had to be operated that fast. The doctors had comforted them with saying that normal time for operation on children in these matters is 1 year. In retrospect the parents are not sure if the doctors said this for comfort (hide the “real” situation) or if they really meant it.

The parents did not receive any information on how to treat the child before the operation. The parents were to a large extent left alone.

“In the period from the disease was discovered we missed getting information and help that could have comforted us. We tried to browse on the Internet, but the information we

found was very frightening. We did not have anyone to call, and lacked any contact point in this period”

The doctors and nurses at Rikshospitalet were relaxed and this comforted the parents a lot, but there are problems related to this relaxedness as well. Doctors, nurses and other see these “special cases” so often that it tends to be “normalised” for them, meaning their focus on the individual tends to “loose” the focus on a group of individuals. Maybe this was the reason for not informing the parents “honestly” on how the situation was. The parents think that the doctors at the hospital were not fully honest about the process after the first consultation.

The follow-up process after the operation is important as well. The parents need information regarding how the children shall behave after the operation, that is, how much they should be “protected” from normal activities. In these matters as well, the parents have encountered problems:

“The two doctors tend to say different things. One of them says that it is perfectly safe to stay, and play in the kindergarten. The other says that the child should wear a helmet, and be careful when he plays and runs. The first one says that I do not need to stay at home to look after the child, while the other says that I should get economical funding for this. We applied for economical funding for me to stay at home, but the first doctor did not approve, and said that the head was 100% ok. This was in fact based on a “white lie” in that they later admitted that the suture was not properly closed in the actual period.”

This means that it was not safe for the child to play “freely” like other children. The family has landed in some sort of political “struggle”, and their child was at risk.

The kindergarten did not let the child attend, as they were afraid that he could be hurt, and that this could give them compensation responsibility

(I-P1-251005, TI-100206)

VIGNETTE 3

The next patient had a tumour in her head, and met the expert doctor in 1996 alone. She was then a teenager. Her boyfriend was not there. The doctor dissuaded strongly operation, and gave her a lot of information on why (the information emphasized his point of view). The doctor wanted to postpone the operation for two years. The operation could lead to her getting disabled. The operation would have the same amount of danger two years later, but as a student she would not get insurance, while she as a worker would have received insurance (students do not have the best law protection regarding this, and the doctor meant that it would be better for her having the status of worker if the operation would fail)

She did, however, demand operation. She did not like the thought of postponing the operation; to wander around in insecurity for two more years. After some time they became frustrated over her as a patient, but she thought that because they had to “go in” and take a biopsy anyway, they could at the same time perform the operation. She got the message that she could get blind after the operation, and all the risk factors were given to her. The operation went fine and some tests were taken (biopsy). The doctor could afterwards give her the good news that the tumour was not maleficent. The girl was in addition a part of a SINTEF project, she collaborated with two researchers before and after the operation, and they filmed the operation itself. Because of this she felt that she was not alone, that she had someone to talk to during the hospital stay. She adds that nurses are “gloomy” in that they know everything about the disease, but cannot say anything. The important thing is however that she strongly affected her own treatment process, what should be done, how and when. She even took the courage to go against her doctor insisting on him doing what she felt was profoundly important.

A “sequel” to this story is the fact that the girl’s brother got a tumour in the head two years later. The girl and her family had now, during the girl’s treatment process, gained knowledge on cancer in the head, treatment possibilities, and were accordingly better prepared. Nevertheless was the type of cancer her brother had more serious. The ”team” who had tried to persuade the girl not taking the operation earlier, did now “proclaim” operation very much in the brother’s case. They gave advices which were in opposition to the ones given to the girl. Unfortunately, the brother did not make it, he died.

(I-201205, MA-070206)

VIGNETTE 4

The fourth vignette is about a couple who encountered great difficulties in their child's treatment process. The doctor did not agree with what the parents said, and they had to "force through" the right to consult another doctor, in order to treat the child:

"Our situation was quite complex. The child started crying and was sent to Ullevål with huge cramps. We had seen that something was wrong with the head but we did not get any understanding from the doctor. The doctor said that the head is formed like this because the height of his father. We had to ask for a second opinion, and we had to do these things ourselves. This first wrong diagnosis became later a case for the controlling doctor in the county"

When I asked why this had happened, and what the problem was, the mother said that:

"It is because of time and money pressure. The doctor is often putting the responsibility of the decision in the hand of the technology, and trust the x-ray pictures more than what we as parents are saying; sometimes he even trusts the technology more than his own eyes"

Information from the Internet was and still is very important for these parents. They participate in "virtual" communities with other parents in the same situation:

"The parents we have contact with has children with synostosis, and we have met them at closed user forums on the Internet. We knew one of the couples before, and meet them whenever they are in Oslo for further checks and controls. This child has synostosis syndrome. The web forum named www.nybaktmamma.no has a sub-category named "children with special needs" where there are several links with children operated for synostosis".

Can you tell me what the possibility to use Internet to interact with other parents does for you?

“I think that things get easier. The world gets smaller and it is easier to find out things on our own. It is however important to consider the validity of the information and this can be a challenge. Getting in touch with other parents in the same situation makes the process easier for us; we are more “visible” to each other. This enables contact between parents positioned on different corners of the world. Internet enables contact whenever we want. On the net we can look-up information written by other parents or at medical sites where there is research material and unpublished material”

How does this affect you, how does it help you?

“We exchange information and experiences. We send links that contain adequate information about the diagnosis, the treatment forms, the prognoses and so forth. Examples are American children hospitals¹⁴. On these pages there are often pictures of patients with different diagnosis, and also pictures from operations. In this way we as parents can sit home in our own house and increase our own level of knowledge (provided that the information is adequate and real, it is important to be critical towards what we read). I always compare this information with information from den Norske Lægeforening and Rikshospitalet”

Does it affect the conversations with the doctors?

“This way it is much easier for us to evaluate the doctor’s decision and evaluation. In our situation it was information like this (from Den Norske Lægeforening) that was determinant when we demanded a second opinion. We had concrete pictures and used them as a comparison with our own child.”

“When we think of how difficult it is to get the opportunity to talk to competent doctors when **we** want it, on **our** premises, it is very comforting to have access to information elsewhere. We now try to help others who are insecure and uncertain regarding the

¹⁴ <http://www.kidsplastsurg.com/craniosynostosis.html>

evaluation from GP/ health station. I recommend to be persistent, and to trust your “gut-feeling”, and to do not give up until you feel safe regarding the evaluation that is done.“
(I-P1-221105, MA-030206, MA-070206)

I have in this chapter described how hospital professionals like secretaries, nurses, doctors, produce use and share knowledge. I have also described how non-human artefacts like technology, pen, paper, telephone is important “partners” in this production, use and sharing of knowledge. Further aspects of lay knowledge amongst the patients and parents were described. The professionals and lay people interact in the treatment process, and thus narratives of how the interests of the different actors are translated, or not translated, into the treatment process were given. This will be elaborated and analyzed in the next section.

ANALYSIS

In this chapter I will first give a brief introduction, before I describe the work tasks and knowledge perspectives of the main actors at the clinic and how they create, use and distribute knowledge. Within this knowledge application, use and distribution technology has an important role. Further I will analyse aspects of knowledge amongst lay people, and technology plays an important role also here. Finally an analysis of the interaction between patients, parents and doctors seen in Vignette 1-4 in the Empirical chapter is given, in the light of the theoretical framework of ANT.

5.1 Introduction analysis

As we saw in the theory chapter first (section on institutional structures) and the empirical chapter later (section on the treatment process), the way towards the expert institution is conditioned by bureaucratic referral points. This can be seen as a part of the process of categorizing patients, and has thus some power elements related to it: the expert hospital can be used only in specific occasions, and the criteria is decided and used by the system in order to decide who can enter. This can be seen as obligatory passage point from the outside to the inside. The institutional structure, the objects, non-human actors like technology, and the subjects like human actors or people, form together the working environment.

As we saw in figure 4 in the empirical chapter my fieldwork was performed within a department at an expert hospital and this department have also **obligatory passage points**. Further the resources has to be ordered and attached to the trajectory (treatment process), and when these resources are available the patient has to be treated in a certain way in relation to available resources. Discussions and negotiations between doctors, nurses, secretaries and patients or parents based on internal and external notes, x-rays, conditions, etc forms the treatment process.

Even though this can be seen as a relatively democratic process, where every human actor participates and makes his or her impact, the process is also largely influenced by schedules, budgets, available resources, working structures, technology, colleagues, Internet, an earlier discharge letter etc. The different “artefacts” or “technical” actors are very important in the human actors practice, that is, the human actors utilize the technical actors in their work practices. Because the technical actors, like technology, is an integrated part of the practice or action in an organization, structures and techniques tends to shape human practice as well. Human practice utilizes technical actors, but these technical actors shape human practices. That is, we use both objects and subjects in our practice. What implications have this on the professionals, on the lay people, and on the interaction between them? This I will further discuss in next sections.

5.2 The main actors in patient treatment process

In the last section I analyzed aspects related to the entrance into the hospital, that it is not a place anyone can approach and get treated. Several requirements have to be fulfilled in order to enter. In this part I will analyze aspects related to the human actors, how they obtain, use and distribute knowledge and how Information Technology is used in this work.

The process of treating patients who has been transferred to Rikshospitalet are not a simple, structured and defined task, but an iterative process where different actors is involved, create relations through collaboration on specific tasks, relations which afterwards may be dissolved, before they are re-formed. These relations are created based on the knowledge human actors have about what shall be done, and how it should be done. For a secretary this may imply how to locate internal resources, for a nurse how to cure and care specific patients who is uncomfortable, for a doctor how to locate and fix a physical problem, for a patient or parent how to communicate feelings, sensations and experience about how the disease affect him or herself. This is issue is mainly dealt with in the empirical chapter, but I will now briefly highlight what we saw earlier.

5.2.1 Secretaries, nurses and doctors as professional actors

Secretaries

The secretaries have some sort of embedded knowledge where routines, rules and regulations are important aspects. The knowledge on how these routines shall be performed is however to some extent embodied, in that it is routine performances intuitively called upon in situated practice. In their knowledge production secretaries utilize technical actors like Information Technology, telephone, papers notes, what Moser and Law (2006) calls ‘materially heterogeneous’ and ‘fluid’ work in that it is context-dependent and contains of both information and materials as images, letters, conversations and physical movements’(ibid: 9). The secretaries are also bureaucratic referral points which has to be accessed in order to enable entrance into the expert hospital for the patients.

Nurses

The embodied knowledge of the nurses is important to make the stay at the hospital less traumatic for the patient. First, they remove the coldness of the technology (Sandelowski 2000). Secondly they implement nursing aspects like care, comfort, and focus on psycho-social elements by maintaining the ‘professional socialization and adoption of nursing culture’ (Moen 2002:293). Nurses are however also the physicians third eye when performing professional patient treatment (Sandelowski 2000), and have to, in contemporary society, to categorize patients across individuals in what Mintzberg (1983) calls pigeonholing. The nurse’s knowledge are mainly embodied but also to some extent embedded in routines and encoded in paper reports and EPR systems. The nurses embodied part is however the most important aspect of neither care nor cure is easily implemented in routines or encoded in digital artefacts. The embodied knowledge is a combination between cure and care learned through training and experience. This embodied knowledge is thus to some part based on knowledge on several patients categorized in order to be able to treat as many as possible. There is then a continual struggle between how to treat as best as possible, and how to treat as many as possible. The knowledge is thus not purely based on individuals or purely objectivistic based on medical “facts”, but a combination of pre-determined curing factors, and individually dynamically determined caring factors.

Doctors

Doctors are scientists who focus a lot on evidence, bureaucratic confirmation of techniques and their own experience. By the bureaucratic confirmation of techniques I mean that new techniques have to go through a relatively inert process in order to be accepted, or seen as evidence. The doctors trust the “well-proven” rather than innovative technology. Examples are the feather technique mentioned in the Empirical Chapter section 4.5.1. The more liberal Swedish health system has approved the technique, but the Norwegian surgeons are not convinced. Further the doctors provide scientific information, but also partly social “comfort” based on the scientific “facts”. It is comforting for parents or patients to receive factual information from the doctor. The doctor has time constraints, is very busy, and the parents welcomes with “gratitude” encounters with the doctor. Doctors use Information Technology to read and discuss on patients (when deciding operation time, treatment strategy etc). They do also use specific technological instruments in their practice. The doctor has the ability to see, define and understand bio-chemical processes in the human corpus. This is a very special knowledge which often is very, very important, but which sometimes “blur” the doctors ability to see the “obvious”. Examples of this could be seen in the Empirical Chapter, section 4.5.3, vignette 4, where the doctor is clearly conditioned by the problem in balancing technological professionalism and relevant knowledge from lay people.

As we saw in the theory chapter the professional scientific work of the doctor is based on technology both for identifying, give name to, and cure diseases or sufferings. Technology are thus an integrated, a complex part, of both seeing and deciding on what is seen. The irrationality of the outside world can sometimes be understood as noise, rather than relevant engagement. The doctors is very occupied in stressing that each occasion, each patient is particular, and that information gained from the Internet is very general. Each specific case has its own specific variant of diseases. The doctor has the ability to identify specific diseases and prove them with technological artefacts like for example x-rays. The interesting issue for the doctor is the physical world and how the physical problem is dealt with. The psychosocial world based on feelings, moods and temperament is not aspects all doctors are much occupied with. This he leaves to the nurse or others. We can see from this that the scientific knowledge of the doctor, where rationality and control is important, where the definition and understanding of bio-chemical

processes and the tentative to cure the disease by controlling the processes is an important part of the treatment, but that it can also create a view of outside “irrationality” as irrelevant.

Doctor’s work

The admiration and focus on science is a basic underlying element of the doctor’s knowledge. Further the task of negotiation and decision making implies what Ellingsen and Monteiro (2003) calls enactment, orchestration and organization of the work. This is about both using the knowledge they already have in the light of new knowledge, to look at knowledge from different viewpoints and to coordinate different tasks to different workers. Some of the doctors are better than others to integrate knowledge obtained from patients or others professionals, into their decisions. These situations can be a base for altering the initial point of view, that is, the parents or patients information can be used together with the more scientific information in order to identify important aspects of the disease and its treatment. The different clinical personnel are also gathered in meetings to discuss on patients. Information about the condition of specific patients is displayed on big LCD screens. Information gained from this is completed with information, written and verbally from for example nurses. The doctor decides, but the sum of information gained from several sources is collected and reflected against the background of “old” knowledge. The organization and collection of different sources is thus done in order to reflect the multiple perspectives of information, on which a fundament for decision is made. We can thus see that the technology, different types of information, objects and subjects emerge as partners which together perform action in deciding what should be done to the patient. The professionals are working as a team, and use different types of equipment in performing team work.

In contemporary society, the professional network is not only seen as scientists but also providers of services ordered by a client (the patient). The increasing focus on value creation creates tighter schedules, efficiency measuring, and can lead to less quality. The existence of additional interests in the scientist’s domain interferes with the technical matters of curing the disease.

5.2.2 Interaction between professionals and use of technology

The professional actors' knowledge is then called upon in situated practice, which relates different actors to each other, and has its roots in the context of interaction in or between communities of practice. It is highly dynamic (Tsoukas and Mylonopoulos 2004:7, Gherardi and Nicolini 2000, Orr 1996, Brown and Duguid 1991), and materially heterogeneous (Moser and Law 2006). The different communities (doctors, nurses, others) have their own specific culture and knowledge and these knowledges and perspectives are often obtained used and distributed within their specific community. In relation to the patient treatment process, the actors meet across communities in order to perform collective action in treating the patient. There is then a "meeting" between different internal sources and communities in order to treat the patient. As we saw in the empirical chapter secretaries negotiate with doctors in order to attach necessary resources to the treatment process. The nurses and the doctors discuss and reflect upon patient conditions and the evolution of the treatment. On the basis of this decisions are taken. Technology is an important actor in this performance. The participation of several actors in performing patient treatment is a type of knowledge sharing which secures that several aspects of the treatment process are fulfilled. The knowledge is to some extent distributed to non-human objects. When for example the doctors (who reads into Dicom) and the secretaries (write what the doctor reads, into EPR), the doctor and the secretary has taken the form of objects which exchange knowledge. When the nurses and the doctors read, reflects and discusses upon new information on the basis of "old" information, their knowledge is to some extent distributed to reports (within EPR, or on paper). These reports are actors which helps the human actors "remembering". The human actors have transferred some of their knowledges, their perspectives, to standardized reports which secure the resources needed in order to perform patient treatment. The standardized nursing reports are nurse allies, and have to be enrolled into the network which discusses patient treatment. The perfection and structure of the secretaries in writing secures the maintenance of standards in the scientific reports. This precision enables a possibility to use the reports in discussions and negotiation between several human actors. The secretary knowledge on precision and structure is visible in the reports, but it is to some extent black-boxed and objectified. The network which performs action in discussing, negotiating, reflecting on how to perform treatment, what has been done and what needs to be done, benefits from the objectified and black boxed abilities of each different actor in the network.

The increasing extent to which technology is used in portraying important aspects of each different actor, does however imply the presence of market-economics as well. The different knowledges were earlier positioned in the local setting or in paper journals. Scientific medical technology formerly locally placed within special units, and accessibly only from specific terminals, can now be implemented and thus made accessible for more general interest. The different actors could earlier “control” the access performed by external actors to some extent. Now there is availability to the previously local information, as the EPR is accessible for the hospital professionals, as well as for hospital management. The presence of management and market-economics has an indirect effect on the performance of the professionals in that it defines quality and treatment in manageable entities and measures the performance on these entities. The quantification of performance affects professional knowledge in that it does not remain “purely scientific”. The network consisting of human actors like doctors, nurses and secretaries and non human actors like standardized reports, Information Technology like EPR, screens, chairs and tables are thus conditioned by additional actors “hidden” in the background.

The EPR and other technology is thus a part of the knowledge communities, and facilitates interaction between communities in performing patient treatment (See figure 5)



Figure 5 : Participation across professional communities

5.3 Patients

In figure 5 above there is an important element lacking, namely the patient. The patient has in some sense become objectified within the technology and the different standardized reports used by the professional human actors. Traditionally patients are portrayed as passive receivers of treatment performed by professional actors. My point is that is not so any longer. The patients or

parents provide in fact valuable knowledge when the different aspects of the treatment are outlined. The patients and parents are important providers of individual knowledge (Figure 6)



Figure 6 : Participation between professionals and lay people

As we have seen, there are many different ways to describe the aspect of patient knowledge and participation in the modern society. The “modern patient” is often seen as a consumer, who has to be given all relevant information in order to choose the best possible product for him or herself. Others see this as problematic, that the consumer society is increasingly complex and that risk creates sickness or at least great difficulties in finding suitable products or services. The patient is a part of the general consumer movement, and this increasing tendency of client participation has certain effects. My aim is however to “go beyond” these descriptions, and look at how patients and parents think about the interaction with the doctor, what are their focuses, motivations and perspectives, how do they perform in order to increase their knowledge, hence, what are their interests, how are they acting in order to stimulate these interests, and how do they act in order to “inscribe” these interests into the treatment. First I will describe aspects related to how hospital professionals and patients/parents perceive Internet information. Further I will outline aspects of patient knowledge and perspectives, before I elaborate on the interaction perspectives as seen by the parents

Hospital professionals, patients and Internet

The increasing expectation regarding that patients take care of themselves, provide themselves with information and make the right choices can be seen as a part of the consumer movement. This implies that ‘patient-citizens should represent themselves in the places where healthcare organizations are managed, and rules and regulations get their shape’ (Mol 1999:85). This situation is enforced by the arrival of Internet. Regarding special sufferings and disease, the Internet is just partly helpful. The Internet is however an important enabler of information to lay

people. The professionals see the information sometimes as threatening and sometimes as “noise”. They do however also sometimes see Internet use as an obvious right patients have in order to inform themselves about their own health. The Internet has created an institutional tendency of critique amongst the professionals at the clinic. Especially the nurses and the doctors have limited admiration for information obtained from Internet, and brought in to the hospital network by the patient. Some of the health professionals see their power as diminished by the information gained from Internet. They use argumentations like “information creates noise”, “it makes patients focus on future hypotheses instead of concentrating on here and now”, and “it makes them scared and frightened”. When dug into the matters a more reflected image is revealed however. The patients bring with them information that “even their doctor did not know”, “information about specific treatment methods from Sweden”, and information which enriches the professional network as well. The administration has tried to establish some sites like [craniofacial.no](#), but admits that these are not adequate at all. They try to identify resources and actively use these resources in order to create a usable web site accessible for lay people like patients and parents. The administration personnel are as well active in appropriating incoming questions (through e-mail) in order for the doctor to respond to them.

Although some of the parents I interviewed had difficulties in finding much information regarding the disease of synostosis, and some experienced the information as difficult and scientific with many medical terms, Internet is seen as a possible provider of information in relation to the disease. Information about diagnostics, narcosis and other practical issues regarding the hospital and the department is looked up in order to be informed.

We can thus see that there are some differences between how health professionals like nurses and doctors and administrative personnel like secretaries looks at Internet information. The more conservative attitude from the nurses and doctors can be seen in the light of diminishing power, while the secretaries have to strengthen their own position now that outsourcing of administrative activities (like writing of standardized reports) is a actual treat. The patients use Internet to a certain degree, but have the need for more specific and appropriated information as well.

Internet is then an important actor in “handing” information to lay people. The information is sometimes turned into knowledge and brought into the network as a part of the general lay knowledge. The lay people like patients and parents use information in order to preserve personal interests. I will now turn to this issue

Aspects of patients and parents knowledge

My findings regarding lay knowledge is based on three aspects of personal or local knowledge; in relation to physical, psychological or socio-economical implication of the disease in the patients or parents life. The patients and the parents have knowledge of their **physical** situation in relation to the disease. Regarding parents, they know how the children acts and behaves, and how their appearance changes. They have knowledge about how their children appear in the everyday life. They are seeking information in several forms from external resources. It can be that they talk to the general practitioner or doctors at the local hospital, they talk with others who have encountered similar problems by using Internet or meeting with them, or they do in other ways use different type of resources in order to increase their own knowledge on the disease. In addition they are **psychologically** affected by the disease. The disease “breaks into” their lives in a way that affects them, makes them insecure, which again can make them seek comfort. This results in that they gain knowledge about their own or their child’s feelings in the situation, and how to seek comfort, trust and security. Thirdly they may or may not have **economic or social interests** which can be affected by the situation. It can be that the disease may give them a new life situation (caused by point one and two) which again can force them to do changes.

The continual change, switch and balance between these three aspects of local knowledge imply what Cussins (1998) calls an ontological choreography. We do not have one streamlined mode of ordering which associates all interests. Rather, these interests like the knowledge of the physical, the feelings, and the knowledge of our economic situation is continually revised. We revise and reflect on them dynamically as we go. Our reflection implies objectification of certain matters in order to manage subjectively. Sometimes our feelings can be more important than economical matters, that is, we might follow our feelings rather than be “rational” and “reasonable” in relation to economical matters. I will return to this discussion in section 5.4

We can thus say that patients and parents have a local and personal knowledge on how the child acts, looks, and how the family's socio-economical situation is. The mother has for example some type of embodied tacit knowledge which regards feelings, hunches and moods both felt by herself in relation to the child, and understandings obtained through daily observing the child. This knowledge is not necessarily rooted in rationality, and is deeply individual. The professionals has to balance the professional knowledge with the individual knowledge in order to treat the all the patients who is transferred to the expert hospital.

5.4 How Interaction patient-doctor shapes the patient treatment process

We have now seen the different human actors, their perspectives and how they use technology to perform in order to carry out their jobs. We have also seen how Internet is looked at by professionals, and how lay people use Internet. In this part I will analyse several perspectives of the interaction between doctors and patients/parents. I have previously drawn up some aspects related to the differences in focus amongst these actors. I will in this part try to bring on important elements in their interaction. **First** I will bring in some elements regarding historical implications of patient-doctor interaction; what is seen as important elements, **secondly** I will discuss the direct implication of the elements mentioned in the previous sections (on doctors and patient knowledge)

As we saw in the theory chapter there are basically two extreme view points in the discussion on patient power. The first states that patients should know everything and that the power imbalance between doctor and patient must be equalled. The second was on how professionals cannot reveal the whole "truth" because this can give unwarranted anxiety to the lay people. Wiener et al (1980) opposed this viewpoint saying that 'the issue should, rather than question the arrogance of the surgeon be, how does 'specialization and dispersal of care doing both to the surgeon's role and the patient's care' (ibid: 35). My analysis is then on the contribution of the parents or patients, that is, how their different types of knowledge – what they have knowledge of – is tried included into the discourse which again could or should make an impact on the trajectory. In short I try to describe how the patients or parents enact together with the professionals in establishing a "secure" patient treatment process.

5.4.1 The implications of combining doctor and patients/parents knowledge

This section has as its aim to see what happens in the interaction patient-doctors, and how issues (interests) which arise are dealt with on the spot. The interests are the concerns of both the doctor and the patients and they have to be negotiated and agreed upon in order to align the network

In the section on doctors (surgeons) knowledge, and in the theory chapter, I talked about scientific knowledge, and in the part on patients I talked about local or lay “based” knowledge. Important elements of the different actor’s behaviour and “strategies” are their interests. Interests are for the doctor typically focuses that goes beyond the scientific knowledge, for example economical, organizational factors which again causes time constraints. The scientific professional and embodied knowledge are then conditioned by additional factors. For the patient and parents I have already mentioned the implication of socio-economical factors, the knowledge of appearances (physical) and the psychological aspect of the local knowledge. It is then not merely about scientific versus lay knowledge, but about interests and goals. The focus of the professionals and the lay actors are embedded in these interests. The doctor has interests regarding institutional demands, the patients and parents tries to translate their needs, their feelings, their agendas, in short their interests, into something which can be implemented and used in the treatment. These different interests influences the treatment process

So what does these interests consist of? How are they called upon, and how do they, directly and indirectly, affect the patient’s treatment?

We can look at the process as one that has as its goal to enrol and align the actors in the network and perform the treatment. But the treatment is continually created as an enactment between different actors, not a pre-existing objective entity which has to be fulfilled

The clinic was created in order to move the patient from their homes where they were “bedside patient”, to an environment where she or he could be treated. A good organization of health system was supposed to erase disease once and for all (Hofmann 1993). The Information Society

produces a lot of information. The information leads to knowledge, but as Giddens (1990, 1991) notes, the knowledge has reflexive tendencies in that new knowledge shows us that the problem we initially tried to solve was not “the real problem”. The expert professionals (like surgeons) are conditioned by this in that their knowledge is increasingly challenged by other expert’s knowledge. Disease is not erased, it has not disappeared. Technology has potential of giving prolonged life, of reducing disabilities and improving life quality (Hofmann 2001), while stretching out lives and trajectories (Wiener et al 1980). The clinic thus has not removed or erased disease, rather, new diseases has been “uncovered” and new ways of focusing on disease has aroused. The information and knowledge on disease is thus not an objective fact positioned within a specific clinic and amongst professionals. Rather, lay people like parents and patients navigate between different sources of information in order to identify information relevant for their situation, but the knowledge may or may not be relevant for their child’s disease. Sometimes this leads to more successful results, other times the information is only “noise”. The goal is the same, to enrol patients and align interests, but the challenges are others.

The alignment of networks

Further I will use the four-step process of early ANT, in order to describe the process of enrolling and aligning interests in the treatment. The implication of multiple interests enforces a focus on late ANT as well. Late ANT has a vocabulary which helps us understand and describe the reflexive nature of contemporary consumer society, and gives us a possibility to easier understand what we deal with.

Step 1 Find a common problem

This step is about finding a problem which is common for the actors. The patients who arrive at the hospital have already gone through several initial referral points, and their problem is thus already “tested”. The doctors (general practitioner or from local hospital) have as well checked up on the patients, and on the basis of received information decided what actions which could possibly be taken. The doctors and the parents/patients have thus a common problem to solve. The point of departure for all the Cases I have referred to was that the child possibly had a

problem, a disease, and the parents or patients needed expert doctors in order to fix it. We can of course say that the common problem can be refuted by each of the actors. The doctor can say: there is no problem, or they can disagree upon what is the problem. I have here defined the common problem as a requirement for even entering into the clinic, and see further problems related to the disease as belonging within a later stage, for example that of interestment.

Step 2 Interestment

This step is about defining identities and interests or other aspects, and to the background of these interests try to stabilize a network. The actors could however have other interests elsewhere, that is, other types of interests which not automatically fit in with the ones at the clinic. The task is then for the professionals to stimulate the actors to follow their interests, or in contrary for the lay people to stress their interests in order to get the professional network to understand them. The multiple interests of the actors thus have to be continually negotiated.

The doctors are “inspired” by their own ability to perform surgery, and research on surgery techniques and technology, but they are also constrained by time schedules created by economical budgets in an increasingly “busy” working environment. The patients/parents have as noted, also several interests while balancing between themselves and their environments, their own personnel needs, and what others expect from them. The Internet has both complicated and simplified the interaction between hospital professionals and lay people. Internet brings with it an enormous amount of information which has to be sifted and appropriated in order to be relevant. It is not always easy to perform this filtering when the medical knowledge is not present. Internet can, however, also most definitely be a medium which can improve the patient knowledge, but it is a medium who challenges traditional role structures.

The patients and parents have interests of their own which do not necessarily fit with the doctors interests, and these can, as I have mentioned, be socio-economical or psychological or knowledge about physical appearance.

In the vignettes 2-4 we can see that they all encounter some important issues in this part of the process.

Vignette 1:

The first vignette demonstrates how “distinct” and determined the parents are to respond when they feel the doctor is wrong in his expressions. The parent (and obviously friends, family or others around her, since she is saying that “everyone can see” that the child’s head is bigger) has detected a worrying rise in the size of the child’s head, and is sure that this is caused by an early enclosure of the sutures (synostosis). The doctor adjusts himself, checks again, and does in this way “makes the parents interest his own”. If he refused (like the doctor in Vignette 4) then the treatment process could be at risk. The parent reacted to a change in the physical appearance of the child, while the doctor first trusts his x-ray pictures, but then adjust himself and performs an additional check, by measuring manually the childs head. This was trigged by the parent protest.

Vignette 2:

In the second vignette we can see that the process never gave the parents the calmness and comfort they were seeking. First they were referred to another family who had experienced the same disease. They were happy for being able to communicate with others but they did not get what they expected. Instead their process was increasingly stressful after this occasion. Secondly the doctors tried to calm them down by saying that everything was fine and that their child did not have to be operated before one year later, while they in the “background” nevertheless, set up time for an operation two months later. Thirdly the “follow-up” process is conditioned by a disagreement between two doctors regarding how the child shall behave in everyday life (playing, kindergarten etc). These parents were and are interested in verbal and written information which they can trust, but do not feel that they have, to an appropriate degree, received that. What is missing is the presences of oral or written information which can help the parents understand and trust. The parents “hunch” that something is not quite right, is only partly faded and put in the background. But their fears and worries are continually re-established. The importance of trust and comfort has as far as I can see conditioned the mother to some extent. She seems a bit sad, and sorrowful, and I think this has affected the family’s everyday life.

Vignette 3:

The girl in the third vignette had a tumour in her head which could possibly be maleficent. The doctor's argumentation was that they should wait two years before operating. This argument was funded in economical advices from the doctor to the girl. If the girl, then a student, operated and became disabled, she would as a student receive little funding from the health system. If she waited until she had a job she would be funded by the insurance system. The doctor had (seemingly) socio-economical interests on behalf of the girl. But the girl had other more immediate interests. She did not have the "nerve" to wait to see if she would spend the rest of her life as disabled or not. She resisted strongly the advices from doctors, nurses and others, and made them frustrated. This did however create a detour, in that she changed the presumed direction of her trajectory, and lead it into another path. This path was chosen by the girl to the background of herself not being able to wait two years until she knew if she would die soon, or not.

Vignette 4:

The parents in the fourth vignette were not ready to accept the doctors reading of facts as correct. They felt that their main interest, namely the curing of the child (they were sure that the child suffered from synostosis), was seriously threaten by the doctor, and that this could harm their child's future health situation. The doctor was not interested in operating since the x-rays did not reveal anything. The doctor's decision was however interpreted by the parents as caused by time constraint, and tight budgets. Other interests interfered and caused difficulties. The parents brought with them a scientific article from a well known journal, and showed the picture to the doctor. The parents did not accept the situation, and consulted a 2nd opinion. This initiative created a detour which changed the direction of the treatment process. This detour is very extensive as it both included switching from one doctor to another and from one hospital to another.

Step 3 Enrolment

The enrolment is about how the different interests is discussed and tried covered through negotiation. The interests can be covered through many different strategies. One can argue that historically the presence of the doctor was enough to "force" the patient to participate (though

passively) in the treatment. Contemporary society enforces a different strategy regarding this. The different interests have to be negotiated and discussed, and this implies calling upon different knowledges about particular aspects of the treatment process.

Vignette 1: The doctor listened to the parent and checked if there was something the x-rays did not reveal. We can thus say that the doctor enrolled the patients into the hospital network, but we can also see that the child, represented by his spokesman the mother's knowledge, interfered into the "pure" technological scientific apparatus of the doctor, and created a detour. This detour implied putting a specific focus on the evolution of the boys head. It made operation more probable.

Vignette 2: The parents in vignette 2 are looking for comfort and security. The several actors which are enrolled into their treatment process do not produce the necessary support. They would like to trust something or someone, but every time they seem to settle down, some additional aspects seems to enter into their path. Their son's pain which partly ruined the baptism in that it made him scream, took with it additional feelings of fear. The partial trust amongst the parents was constantly replaced by re-occurring anxieties. The enrolment is thus conditioned by a fragility caused by the lack of adequate support.

Vignette 3: The girl persistently demanded that her interests, based on the knowledge she had of her own psychological situation, was taken into account. The doctor's categorization of her as "a patient who could wait two years" did not impress her. She felt that the socio-economical aspect was too weak. The psychological aspect was much stronger. She felt that the hospital professional's intentions were not merely about "taking care of here", but that they had hidden agendas which could surprise her later. She felt that it was her duty to take care of herself. After the hospital network (somewhat resistant) accepted performing the operation immediately, the network was aligned. The girl participated in a research project with researchers from SINTEF, and did in fact give a contribution to the research on equipment used for head operations. The doctors, the hospital community, the researchers from SINTEF, and the girl herself, have learned something from this process

Vignette 4: The parents in vignette 4 refused the enrolment into the hospital network of the first doctor. Their local knowledge on the child's appearance mixed with appropriate medical knowledge obtained from Internet was incompatible with the doctor knowledge at the first hospital. The doctor refused to operate because his network (consisting of amongst other things x-ray images, his own knowledge and time constraints) told him that operation was not needed. The introduction of individual knowledge and medical information from Internet, collected by energetic parents, and brought into the network created a conflict, which again resulted in a detour. The detour resulted in the parents and the child switching from one hospital to another. The knowledge obtained by the parents through continual negotiations at hospital one, was used to secure interests at hospital two as well.

Step 4 mobilize allies

This step is about how the few individuals which participates are mobilized by a central actor in order to obtain success. The degree of success is however conditioned by how important interests or elements are uncovered and dealt with. The doctor alone with his medical apparatus is not longer enough. The presence of active participant lay people enforces an increased focus on the "nature" of these interests. The lay people do not necessarily accept playing second string and bring with them allies in several forms in order to convince the hospital professionals.

Vignette 1: The parent refused to the doctors indications that "the form of the head has not changed". Although the x-rays indicated that this was right, the parent's point of view got assisted by a tape measurer. The doctor's use of the tape measurer helped him adjust his initial point of view.

Vignette 2: The doctors treating this patient have used several allies in order to "cover up" several aspects of the treatment. The parent's re-occurring anxiety has been partly dealt with by the presence of calm and secure doctors, but the parents have suffered disappointment and setbacks all the time. The psycho-social aspect of the process remains partly unmanaged. The family has suffered fear and worries which may have affected their private life. The probable exclusive focus on cure, has affected the psycho-social aspect of the families life. These parents have initial

trust in the expert. The white coat, paternalistic figure and technological equipment of the doctor, in addition to the supporting institutional structure of the expert hospital are for the parents synonymous with expert. They trust him. But the alignment is only partly achieved as the hidden “truths” continually re-introduce the parents’ anxieties.

Vignette 3: The girl preferred protecting her immediate psychological condition; she pushed the doctor to agree on this, and used a SINTEF project as partly comforters for her own anxiety. The doctor said afterwards that she had chosen wisely, and that he was glad everything went ahead as it did. The girl allied herself with the doctor, and the doctor agreed. In addition she participated in research projects on the theme, and the knowledge gained from this can help others later.

Vignette 4: The parents in this vignette used many allies in order to secure their interests. First they used medical information from Internet in order to demonstrate that they were right. They did also involve a controlling unit to investigate their case, as they meant that the doctor performed several errors in his decision making. The doctor tried to use his white coat, his technological apparatus which produced nice and “scientific” x-ray pictures. But the parents were all but convinced. Finally the parents enrolled an important actor, a second opinion, an additional hospital, and the operation was performed there.

I have in this section used an ANT translation strategy to identify how the interests of the patients are translated into the treatment process. The next section contains analyses and discussion on the implications of these findings.

5.4.2 Challenges in combining knowledges when performing patient treatment

In this part I will reflect upon these analyses and further discuss some implications. This I will do in three points, first what is examples of criteria for success in patient treatment regarding use of different knowledges; second what is sometimes the reason of failure in the same treatment. The third point regards how the presence of information everywhere and how increased amounts of information creates new challenges. Success can be seen as ‘an event that accomplished its intended purpose’ (Wordnet 2005). The intended purpose can however be constantly modified in the light of new knowledge. A patient with headache who has as her goal to get rid of the

headache (maybe with the use of tablets) will focus differently when she suddenly finds out she has a brain tumour of which she could die. The processes are successful if the patients' interests which are relevant for the disease are taken into account. The process is however often not longer only a technical or a social one, but rather a socio-technical performed in heterogeneous networks. The success is then also conditioned by how the lay people feel they have been taken care of during process, how their interests have been taken into account. Failure is on the other hand 'generally when a desirable or intended objective is not achieved' (Wikipedia 2006). As Cussins (1998) noted can a quite similar process be described differently by the same woman. If the process went wrong she could say that the procedure objectified her, while she could say different things about a similar process which obtains its goal. This could, according to Cussins, be seen as a process of justification and self-interest done by the woman in order to 'fix the identity [of herself] at the time she is speaking' (ibid: 171). Success in relation to pre-established goals is thus important. But as we now see, failure can also be modified in the light of happenings which occur during the process. If a patient loses vision on an eye, it could be a failure in relation to initial goals. But it can also be success in that the evolution of the disease indicated that the life of the patient was at stake. Failure is then about changing goals, but also about how different aspects of the disease are discovered with the use of different knowledges. If the doctor refuse to listen to the patient and the process is conditioned by this it can be argued that it is partly a failure. Success and failure can thus be seen as a matter of aligning interests. The amount of alignment decides amount of success or failure. The third point questions the view: more information, better treatment. The reflexivity of information as discussed by Giddens indicates that "information everywhere" can create problematic situations.

Obtaining alignment

A successful enrolment of patients thus implies that patients' interests are taken into account. These interests contain knowledges of individual aspects. The scientific knowledge has as well several constrains in that it in contemporary society implies taking care of consumers who demands quality and quick treatment. The objectives of production are mixed with principles of treatment. In order to make a successful treatment process different type of knowledges has to be used. Individual aspects have to be revealed in order to secure the treatment process. The

balancing between scientific approved techniques and “production requirements” on the one hand, while selecting what to take into account and what to ignore regarding what the patient “brings with them” on the other, is an ongoing ontological dance which requires a slightly different focus. The patient tries to enrol several allies in order to emphasize their point of view. The doctor then has to take these different actors into account. The white coat, scalpel, x-rays and bureaucratic access procedures are not longer enough, or indeed maybe it has never been enough. The vignettes one (mother calls doctor statements nonsense) and three (girl who demands being operated immediately instead of two years later) demonstrates how important it is that doctors are flexibly adjusting initial points of view. The first shows how the obvious element of appearance interfered and made the correctness of the x-rays discussable. The boys head has apparently increased. The mother is firm. The doctor is able to immediately “get over” the “loss of face”. He admits the shortcomings of the x-rays and takes from his drawer an old, and for lay people precious object; the tape measurer. This object makes present for the doctor what was previously absent. The form of the head has changed.

The third vignette shows how the girl ignores the socio-economical rational aspects like insurance when her mental health is at stake. The tumour is a rigid object too important to neglect and ignore. The objectification of the tumour (and several other things in her life) makes her able to perform a subjective struggle fighting for her personal interests. She uses her personal knowledge on what she feels and needs. She allies herself with psychological matters in order to convince the professional network of her honesty. In addition she challenges the correctness of the decisions taken by the professional. She feels that they are cynically looking at her as an irrational subject who does not know her own good. She speculates in that the information given to her by the experts is strategically chosen to strengthen their assumptive hypotheses. The professionals finally comply, and perform the operation. The professionals look at the tumour as an object which can be difficult to remove without damaging the nervous system which enables vision, or which in worst case can ruin too much of the brain and make it impossible to save the girl from dying. Because there is a possibility that the operation can disable the girl, the professionals’ claim that she has to think of her future. The girl is afraid of dying, and makes a rational choice based on her individual understanding of her own psychological state. We can then see that there is an ontological dance between the technical and the social, between the

professional knowledge and the lay knowledge. The ability of the professionals to adjust points of views and integrate occurring actors and knowledges into the network implies an understanding of the socio-technical essence of the network. The heterogeneity of the socio-technical network implies a shifting focus from merely managerial, merely technical or merely social view of treatment, to the focus on partial coherency (Law 2003). This implies taking care of thing as they occur, have the ability to shape the treatment process taking several ad-hoc decisions which could break higher level rules (ibid).

When conflict occurs

The occurrence of conflicts during enrolment and the failure to achieve alignment has also some fundamental features which can partly be seen in the vignettes. Vignette number two and four are different but have some similarities as well. First they share the tendency of doctors putting focus almost entirely on the technical aspect of the treatment. This means that the social aspects are to a large extent neglected which again creates some problems in a process of socio-technical conditions. Vignette two gives an example of how the ontological security of the parents is partly affected by the ongoing establishment and breakdowns of trust towards the expert doctors. The parents need security, comfort and explanations, but what they get is continual introduction of elements and implications they did not know about. The trust in the experts fades gradually, but they do not feel they have an apparatus which enable them to protest. The doctor looks at the implications as caused by differing experiences amongst the two doctors. The doctor, who said that the child could play in the kindergarten without helmet, did however later admit that this was “a white lie”. Suddenly a political actor of how to grant sickness benefit to the mother is present. The professionals are clearly conditioned by additional perspectives.

Vignette four demonstrates what Wynne (1986) calls the unreflexive blindness and inadequate models of the human. By this he means that the technical, objective and universal view of humans across individualities tends to not enable the grasping of specific aspects of each one of us. This can be individual factors which intervene into the family life and affect the fundament from which action is initiated. In the doctors view the feelings and suggestions from the parents seems to be looked at as irrationality. The focus on feelings is present, but the doctor will have nothing of it. The technical apparatus he uses, which includes the x-rays, gives a clear picture of

everything needed, he seems to say. What is present is what he sees. He refuses to take into account the possibility that there are shortcomings in his “gaze”. In addition, the pigeonholing aspects of categorization (Mintzberg 1983) across individuals confuse his goals, in that the pressure for production is interfering with the “purity” of treatment. Although the parents enrol several actors as allies in order to convince the doctor, he remains stable and untouched by their initiatives. He proudly and somewhat ignorant remains at his trench. The parents on the other hand do not surrender either. Their focus is on the urgency of performing operation. They are sure that their boy is suffering from synostosis. Synostosis is a disease which can prevent a “natural” growth of the brain, and cause disability. For the parents their only son was in danger. They tried to enrol allies, in the form of medical information from Internet, in order to convince the doctor. But the doctor refuses to accept the additional actors. The alignment never succeeds. The parents goals are not aligned with the doctors goals. The parents do not accept rejection from the doctor and consults a new allied; a doctor at another hospital. The boy is later operated at the other hospital which identifies the presence of synostosis. Figure 7 (below) shows three situations, the first image demonstrates that there are some initial interests amongst the actors. These interests are then tried integrated into the treatment process, but may end with conflict or success (images 2 and 3)

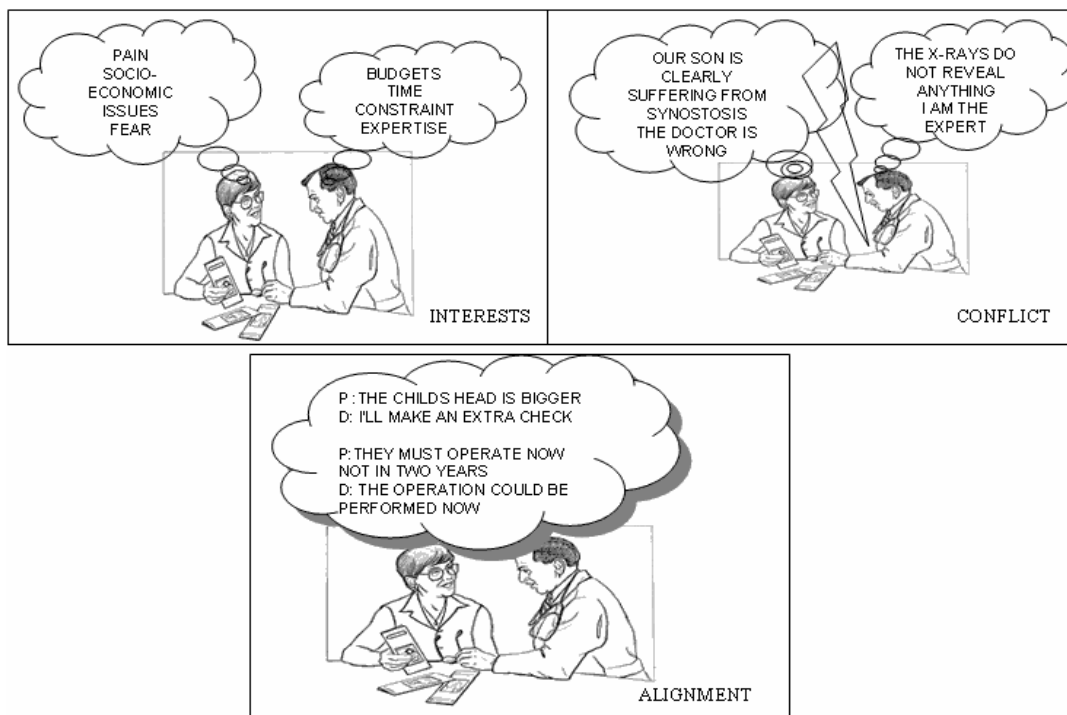


Figure 7 : Translation of interests

The reflexivity of increased amount of information

As we have seen contemporary society with Internet brings with it extreme amounts of information. Hylland Eriksen (2001) claims that this create a timeclamp in that it makes us spend even more time on gathering information and analyze available options. Giddens goes farther claiming that the information has reflexive abilities in that new information challenges the correctness of the pre-existing information and that this questions the correctness of the expert system (e.g. how patients questions doctors' statements). Hoffman (2001) focuses on how the ongoing development of medical technology with increasingly detailed features enables detection of new diseases which sometimes challenges the existing knowledge. Further, the technological concept of disease is about how we see diseases through technological lenses, where the patients' subjective experience is translated to fit the technological semantics. Information is important as a fundament for decision making, but we can see two problematic issues related to this as well. First technology is used to identify new diseases, and this creates new information. Second the distribution of medical information to Internet enables accessibility to "knowledge" for lay people. Both this aspects creates a situation where the hospital network is loaded with increased amount of information. This creates new challenges. The Te@mwork 2007 (SHD 2005) strategy does for example talk about the problem of "ambiguity" and "duplication" of information. Ambiguity is seen as a problem which can hamper decision making. But as Moser and Law (2006) note it is difficult to know in advance how information is used or what will count as information. This means that ambiguity is a part of the nature of information in hospital work. We are then in a situation where we can state that there is no universal and objective value of information which can be defined once and for all. Information has to be appropriated in the individual case. What counts as important information in one case can be seen as irrelevant in another. The diseases have presences and absences (Law and Singleton 2003). This means that there are things which may be visible (the size of the head, a crying children, a tumour), and things which are not present (insurance, time constraints, psychological aspects). What is present and what is absent in the specific case is found through reflection, interaction, discussions and negotiations.

Information from Internet carried by a patient into the hospital network can create noise, which can affect the hospital professionals' ways of working. This can happen in several ways. First patients can bring with them information which by the expert is seen as irrelevant to the specific case. The distance between the disease and the claimed solution to cure the disease is too large. This can partly be seen in the episode where a patient's sister calls the doctor claiming that he can remove the tumour without making a physical intervention. There is no way the doctor can accept this, and he spends 10-15 minutes explaining this to the relative. Of course this can also be seen as right patients or relatives have in questioning expertise. The point is however the amount of time used on this occasion, the distance between disease and relevant solution as the doctor sees it, and the interference it makes into the busy doctor's day. A second example is that the patient brings with them information which demonstrates disagreements or discussions between experts. As we have seen the expert system in high-modernity brings with it loads of information and it is impossible for experts to be 100% updated. The example where techniques regarding using feathers to keep the sutures in the head open demonstrates disagreements between the Swedish and Norwegian experts regarding the relevance of the technique. Internet enables access for lay people to this discussion between professionals. A "quarrel" between Swedish and Norwegian health professionals is then "dragged out" from the medical environment into the general society, and by the lay people carried back into the hospital network. A third example can be a problem Hjortdahl et al (1999) identify. This regards the problem related to 'how long people who have a almost unlimited access to information, but limited access to health services, will accept that they not always will receive the most "modern" and expensive treatment' (ibid:4341 my translation). We can see that some of the nurses encounter this problem in that patients with complex diseases, and where the hospital professionals tries to inform about the actual situation, already are way into future hypotheses (I-4.5-041005). This means that the nurses especially, but also the doctors have to take great strives in order to re-establish the patients view on possible outcomes. A similar problem relate to the quality of the treatment. What is seen as success in one process can be conceptualised as a failure in another. A complex tumour surgery could lead to the loss of hearing. Sometimes a patient can be satisfied only by surviving a surgery like that. Other times this could be seen as a failure by the patient. We can then see that the patients may have different demands, and a struggle between medical institutions which market themselves on Internet, can most certainly affect how each one of us conceptualise success and failure.

From these three examples; the increased amount of questions from lay people to professionals; the medical discussions between professionals which is grasped by the lay people and returned into the hospital network; and the implications of increased demands from lay people regarding health services demonstrates the reflexivity of contemporary society.

In summary we can see that the health system, based on the removal of patients from their home beds to the new clinic (Foucault 1973), and the subsequent integration of discipline into institutional routines (Foucault 1977), created a scientific environment which enabled studying of bio-chemical processes which eventually created methods for cure. The modern society did however bring with it increasing amount of information, knowledge as well as focus on consuming. These phenomena's has created a dynamic but very complex society, and the former paternalistic institutions like hospitals is to some extent challenged by aggressive and determinate patients. While the hospital professionals are conditioned by the need to categorize and structure in order to maintain their abilities to treat several patients, the unique patient holds specific information about several important personal factors. The lay people's knowledges have to be taken into account in order to reveal important aspects regarding diseases. In the interaction with the doctor, the patient-parents does not longer necessarily agree to a secondary role, but rather utters individual opinions, feelings, understandings and points of view in order to secure that their interests is taken into account.

DISCUSSION AND CONCLUSION

This chapter re-introduces elements from the theory chapter, and introduce new aspects which I will like to discuss further. These aspects can be seen as generalizations of the type “drawing on specific implications”, or “contribution of rich insight” from Walsham (1995).

My study supports earlier research regarding complexity of distribution of information (Moser and Law 2006), of knowledge as deeply embodied in individuals performing practice (Suchman 2000, Orr 1996, Tsoukas and Mylonopoulos 2004), and performed as an enactment between actors within or across communities (Law 2000, Gherardi and Nicolini 2000). All these discuss the importance of looking at practical knowledge as deeply embodied and that all the efforts to standardize and structure knowledge work must be rooted in the actual context. This goes well with findings from Walsham (2001, 2005), Thompson and Walsham (2004), Walsham and Barrett (2005), and McDermott (1999) who generally states that technology has to be aligned with, not replace, the “manual” aspects of knowledge work.

Further the difference between professional knowledge held by doctors or nurses, and the lay knowledge embodied in patients or parents, fits well with the division outlined by Wynne (1996) regarding farmers and professional environmentalists. In order to analyse findings from fieldwork, the theoretical framework of ANT was chosen. This enables a view of action as performed between actors (humans and non-humans) from different communities creating networks of relations. By studying networks at a micro level, the knowledges of professionals and the lay people can be studied as it is exchanged. It can be argued that this enables additional insights as well, and I can at least identify six, and these will be discussed further.

Firstly, professional knowledge work is a balance between explicit and tacit knowledge embodied in the actors. The heterogeneity of knowledge work does in addition imply the

presence of non-human actors like technology or other artefacts. This creates a complexity which makes it difficult to see the borders between subjects and objects. Rather, the subject and objects are partners performing action. The different KM ideologies and business strategies do not seem to be affected by this complexity. The teamwork strategy does, on the contrary, talk about free flow of information, changing of work practices and standardization of routines as this was a simple matter. Further, KM ideologies talk of knowledge sharing and knowledge transfers as if knowledge was an object separable from the knower. My opinion is that the management strategies and the technological development processes are based on an outdated view of information systems as “stand alone” applications with its own logic separable from the context. New eras demands new strategies and this regards EPR systems as well. In order to “embrace” external, internal, micro and macro aspects, the information systems must be looked at as information infrastructures (Hanseth 2002). This strategy is a flexible approach which enables the ability to identify important aspects of the installed base and then design an implementation strategy on the basis of this. The CSAM implementation process at Rikshospitalet seems to have some elements of this more “humble” approach embedded in it, and will be followed with interest.

Secondly the treatment is a micro process where different interests are negotiated and integrated (or rejected). The use of the relational framework of ANT enables an investigation of the treatment process as an enactment performed between nurses, secretaries, doctors, and patients (or parents). The absences and presences (Law and Singleton 2003) of the disease are uncovered through a process of common influence. The interests may hold economical and psycho-social elements which interfere with rational “reason”. For the doctor reason can be to perform “pure” treatment unconditioned by time constraints and other interests. For the patient, reason can be to take care of her or himself and behave “responsibly”. This “reason” is continually affected by other “logics” conditioned by economical budgets, time constraints, increased amount of patients, and moods, regarding doctors. The patients “reason” is conditioned and affected by psychology, and socio-economical matters. The interests are a balance between what some may call “irrationality” and “rationality, between psychology and economy, stress and responsibility, dynamically conditioned by individual and contextual aspects.

Thirdly, to combine scientific professional knowledge and lay knowledge enables an increased understanding of the “nature” of diseases and its implications. Timkin (2003) claims ‘that health and disease have not shown themselves to be immutable objects of natural history. Health and disease are medical concepts in the broadest sense. This means that man's life in its inseparable union of body and mind is seen under the aspects of possible preservation and cure. Thus they are distinguished from purely scientific concepts on the one hand and from purely social ones on the other.’(ibid) The patient’s knowledge is thus an important element when identifying diseases. The ability to integrate the knowledge of lay people in decision making is an important aspect of the “modern” doctor. As we have seen in the empirical/analytical chapter the patients or parents bring forward important aspects of the disease which the doctor’s technological apparatus sometimes fail to see. This relates also to the use of different ontological fundamentals. The technological apparatus, the medical gaze, focus on “universal” bio-chemical processes possible to standardize across individual specialities. The individual knowledge is deeply contextual and related to the everyday life of the lay person. This switching between the universal (environment) and ourselves (individual) is what Cussins (1998) calls ontological choreography.

Fourthly, the increased amount of information in contemporary society can confuse the decision making. The reflexivity of information (Giddens 1990) is based on a view that the continual production of information, which turns into knowledge, hampers the trust lay people has towards experts. This is partly understandable as the experts in contemporary society are experts on increasingly specific things, and has less time to investigate continually produced information. This creates situation where experts and lay people has to cooperate in order to reduce the amount of “noise”. The noise can not just be ignored; the lay people will not accept that. “Democracy” in the decision process can maintain political stability and avoid social resistance from lay people who act and protest against overwhelming use of political power.

Fifthly to create improved patient information system is to stimulate increased knowledge amongst patients. There is a lack of adequate information systems which enables patients to access information, and relates it to their own disease. Initiatives like minJournal (www.minjournal.no), a distributed information system where the information is registered and pushed towards patients, as well as other health professionals, is clearly positive elements in

portioning and accommodating personal information to the patients or parents. But its centralized and controlled nature can be seen as problematic as well. The information is basically based on the outcome of official encounters between health professionals and patients or parents. The important information parents and patients brings with them is only briefly taken care of, and used, in the knowledge creation at the clinic. The health system controls all the information and decides what to make accessible for the lay people, although it should be mentioned that information from expert patient groups shall be integrated into minJournal¹⁵. The EPR has however not one integrated coherent owner, but a set of different stake holders¹⁶, and this demonstrates some of the complexity related to the implementation and diffusion of such portals. Other examples are initiatives like REPARERE (Moen and Smørðdal 2006). This is more related to the “ideological” initiatives where there is no central controlled structure. It is a decentralized system where information can be accessed based on certain indicators given by the patient when registering herself. The system distributes information based on iteratively obtained knowledge from different group members, and divides between necessary information and additional information in order to help the user in selecting. The communities of interests like nybaktmamma.no (mentioned in the empirical chapter) have however also important information which could be of interest in a learning process between professionals and laypeople, but this type of focus is almost entirely absent. The important “stream” of information is seen as the one between professionals and laypeople, and not the other way around. The knowledge is to a large extent pushed in one direction: from health system to lay persons. A groupware tool within a portal framework should include information which has moved in the other direction as well. Figure 8 (below) gives an overview over aspects mentioned in discussion above. Information from the EPR systems is spread out towards lay people, but only to a limited amount in the opposite direction (lay people → hospital). The stapled line from patients towards EPR indicates that the information from lay people is only partly taken into account.

¹⁵ The plan is to collaborate with patient groups, receive information from them and integrate it in the myJournal part of the EPR system.

¹⁶ Some indicates that there is up to 20 different stakeholders. These includes both rules and regulations as well as doctors, personnel security rules and juridical actors

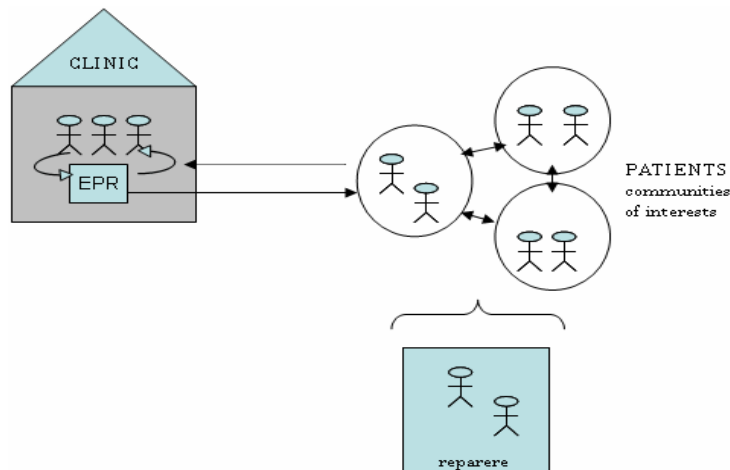


Figure 8 : The structure of information flow between Health System and lay people

The **sixth** point regards knowledge systems. In my thesis I describe knowledge communities as communities of practice which has certain cultural, social and historical focuses. The networks are established across these communities when performing action. This means that interests from actors in different communities have to be integrated and aligned when performing treatment. The knowledge systems are the total amount of communities and networks established inside an organization. In contemporary society the patients can be seen as parts of this system as well, in that they participate in the treatment process. The professional workers and the patients create complex knowledge systems performing treatment.

These six generalizations can be used in other contexts as well. I think these challenges regard all areas where professionals workers interact with lay people.

Further work

The findings in this thesis, as well as the theoretical discussions based on the findings, outlines some interesting further aspects. I will here present two of them.

First the issue of scientific and lay knowledge may be further investigated. The market-economical model transferred also to the Health System, affects the organization in ways that may condition the treatment process. The medical decision apparatus is conditioned by conflicting interests. The lay people sometimes persistent, other times confused and

overwhelmed bring with them different issues into the clinic. This creates new challenges which can be interesting to further investigate.

Secondly the patient information systems for receiving and communicate information should be established in order to create inter-communicative discourse between lay people and hospital professionals. The patient are to some extent often left alone in their anxiety. The stress and the insecurity this sometimes creates can make problematic impacts on the families. Information systems where information is made available for the patients or parents can create some sort of security. The Internet provides information but often this information is complex and medical. The appropriation of Internet is thus an important issue. This enables “outsourcing” of some of the patient preservation work to the patients themselves. This can enable them to treat their own wounds, their chronic diseases, which could generate extensive saving for an overloaded health system. To continue and extend initiatives like REPARERE (mentioned above) is thus of big importance.

Concluding remarks

I started this thesis outlining several challenges the Health System and patients have in contemporary society. For professional worker this regards knowledge application, use, and distribution, for patients the identification of “appropriate” information. Further I looked into how technology is used in the knowledge work at the expert hospital, Rikshospitalet. The patients are often actively engaged in the decision making process and demands that their interests are taken into account. This creates a situation where the scientific knowledge of the professionals and the lay knowledge of the patients have to be combined. This is not always easy. In the different types of knowledges there are both “rational” and “irrational” interests. The issue is then to enrol a sufficient degree of information in the actual situation, so that alignment can be achieved. This understanding has some implications. Lay knowledge of the patients in contemporary society is not based on ignorance and neglect. Rather it is based on the existential need lay people has to participate and affect their own “fate”. They have to take care of themselves. The professional knowledge is not pure science, identification of bio-chemical

processes or deformed craniums, but also a production of services measured, and rewarded on the basis of efficiency. In order to balance the different aspects in the particular situation, different types of knowledges must be taken into account. There is then an importance to create a link between important resources and the lay people, in order to create improved cooperation, and sharing of knowledge, between the professionals and the patients. The thesis contribution is thus that it gives an understanding of the knowledge used in the treatment process, and the challenges the combination of different types of knowledges may lead to. It does also provide insight into aspects of lay knowledge amongst patients at a “micro” level, and how this lay knowledge is used in action to secure interests. This contribution may be used practically, in two ways. First it enables an identification of good “patterns” for communication in the patient – doctor relationship. Some doctors are very good at combining their knowledge with the lay knowledge of the patients. These “patterns” can be shared with other doctors. Regarding the patients, there is a need for them to understand the complexity of medical work as well. Accessibility to information through Patient Information Systems, and improved abilities to sift information can enable an improved understanding of this complexity amongst lay people. The second aspect is the insight it gives into lay knowledge. This insight can be used by practitioners in order to create an understanding of patient aspects, and use this understanding during the treatment process to identify who needs extra amount of attention, information, communication.

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APPENDIX 1

Nr	O	Task	Comments	Resources
1	1	Doctors work related to use of the portal (in operation and consultations)	<ul style="list-style-type: none"> • Portal as information infrastructure • Portal as 'knowledge management' 	<ul style="list-style-type: none"> • 5210 litteraturen (Control to drift) • Ciborra – IS as a phenomena, and labyrinth? • Walsham : par papere om knowledge managment
2	1	Parents – knowledge	<ul style="list-style-type: none"> • Parents opens 'black box' when encountering child disease. This new gained knowledge reshuffles the relationship patient/parents – hospital medical • Risk society – balance • Information positive and negative (access to extensive) • Portal-patient part in this sense, and how information must be diffused 	<ul style="list-style-type: none"> • Cussins -onthological • Beck? – risk society • Foucault Birth of a clinic
3	2	Integration	<ul style="list-style-type: none"> • Integration of systems, especially related to blood samples, • Machines at the patient bed →portal. • Order blood samples from the Portal • Both technical integration, and integration of systems in an STS perspective 	<ul style="list-style-type: none"> • Monteiro papers at his web site (especially under miscannelous) and 'a patchwork planet' • Gunnar Ellingsen • Leo Gasser The integration of computer and routine work • Kling/Lamb - reconcept
4	2	VIPS standardization	<ul style="list-style-type: none"> • Standardization vs. flexibility. • What elements bias the standardization process • VIPS structure (top-down), but participation of people from the 'floor' (bottom-up bias) 	<ul style="list-style-type: none"> • Hanseth/Monteiro tension between standards and flexibilty • Standardization generally, different types of standards • Sorting things out ICD standards, categorization
5	2	Diffusion strategy	<ul style="list-style-type: none"> • How to balance a big system into the heterogeneous network • Differences and similarities between '5210 literature' and actual strategy at Rikshospitalet 	<ul style="list-style-type: none"> • 5210 (Control to drift) • S@mspill • Communication during the diffusion
6	3,4	Complexity at Intake office	<ul style="list-style-type: none"> • How the intake office has to structure and handle different type of situations and exceptions in order to use resources best possible way • Categorization, relationship with customers, flexibility vs. tight rules etc. • Situated cognition? 	<ul style="list-style-type: none"> • Ingunn Moser, John Law – the nature of information etc • Complexity • Brown/Duguid, spoken vs actual practice