

Hannele Kerosuo

BOUNDARIES IN ACTION

An Activity-theoretical Study of Development, Learning
and Change in Health Care for Patients
with Multiple and Chronic Illnesses

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Original articles

- I Kerosuo, H. (2001). Boundary encounters – as a place for learning and development at work. *Outlines – Critical Social Studies*, 3 (1), 53–65.
- II Kerosuo, H. (2004). Examining boundaries in health care – Outline of a method for studying organizational boundaries in interaction. *Outlines – Critical Social Studies*, 6(1), 35–60.
- III Kerosuo, H. (2003b). ‘Auctioned orphans’– Learning from patient experiences of ‘homelessness and ‘abandonment’ in health care provision. 3rd International Management Studies Conference, 7–9 July, 2003. Lancaster University Management School, Lancaster, Conference Proceedings.
- IV Kerosuo, H. (2003a). Boundaries in health care discussions: An activity theoretical approach to the analysis of boundaries. In N. Paulsen and T. Hernes (Eds.) *Managing Boundaries in Organizations: Multiple Perspectives*. Basingstoke: Palgrave Macmillan.
- V Kerosuo, H. & Engeström, Y. (2003). Boundary crossing and learning in creation of new work practice. *Journal of Workplace Learning*, 15 (7–8), 345–351.
- VI Kerosuo, H. Re-negotiating disjunctions in inter-organizationally provided care. A manuscript accepted for publication in *The Discourse of Hospital Communication – Tracing Complexities in Contemporary Health Organizations* edited by R. Iedema. Palgrave-Macmillan.

In the following dissertation, these articles will be referred to by the Roman numerals I–VI.

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Abstract

This study examines boundaries in health care organizations. Boundaries are often considered harmful; things to be avoided in everyday living. This study suggests, however, that boundaries can be important temporally and spatially emerging locations of development, learning, and change in organizations and work practices. Boundaries are established distinctions and differences between and within activity systems that are created and agreed on by groups and individual actors over a long period of time while they are involved in those activities. As traces of past activities boundaries trigger learning and development.

The data of the study was gathered in an intervention project during the years 2000–2002 in Helsinki in which the care of patients with multiple and chronic illnesses was improved. The research project used the Change Laboratory method that enables the development of work and work practices in organizations. The general research question of the study is: What are the boundary dynamics of development, learning, and change in health care for patients with multiple and chronic illnesses? The first research question is: How do individual patients experience boundaries in their health care? The second research question is: How are the boundaries of health care constructed and reconstructed in social interaction within a Change Laboratory intervention? The third research question is: What are the dynamics of boundary crossing in the experimentation with the new tools and new practice?

Conceptualizing chronic illnesses and the care organization of chronic illnesses emerges as multi-voiced in previous studies and the literature. The historical analysis of the study uncovers the formation of the boundaries between professionals and patients, levels of care, specialties, and market based and negotiated care in

present health care organization and shows how boundaries have evolved during the history of health care organization. The historical analysis also illustrates the rise of multiple and chronic illnesses as an object of care and the phases of development of this rise, including the current challenges in Finnish health care. Chronic illnesses presently emerge as complex phenomena involving the intertwining of organisms, representations, and medical technologies. Multiple illnesses, aging, lifestyle illnesses, and medicalization increase the complexity of chronic illnesses, while the health care organization seems to be developing towards a diversity of multiple providers through specialization, market-based development, alternative models of service production, and new types of patient agency.

The review of the literature and earlier studies of boundaries in work, health care practice, and patient experience uncover the diversity and ambiguity of boundaries in health care practice, but studies that focus on the processes of development, learning, and change in terms of boundaries are still few. Therefore, the framework of the study suggests that boundaries are hybrid contexts of development, learning, and change in work and organizations. Boundaries provide potential for development and change while enabling expansive learning, during which the organizations can contribute to the creation of their possible futures.

The methodology of the study, i.e., the ethnography of the multi-organizational field of activity, draws on cultural-historical activity theory and ethnographic methodology. The ethnography of the multi-organizational field of activity makes connections and disjunctions between multiple locations of a patient's care. The focus on 'border zones' between health care organizations brings up aspects and processes of development, learning and change taking place at the boundaries in the multi-organizational field of health care. The ethnographic fieldwork of the study involves multiple research techniques and a collaborative strategy for raising new research data. The data of this study consists of observations, interviews, transcribed intervention sessions, and patients' health documents.

The central findings of the study describe the intertwining of practical activity, development, and learning in organizational development. The 'border zone' between health care organizations is fragmented by organizational and practice boundaries. Practitioners and patients mark the boundaries in their talk. Collective learning can, however, be a process of reconstructing boundaries, and joint reflection enables boundary crossing in the Change Laboratory sessions. The central focus of development is that patients frequently experience uncertainty and neglect in their care. In the effort to improve the care of patients with multiple and chronic illnesses, the questioning and transforming of the prevailing boundaries emerged as a demanding learning challenge among professional practitioners, patients and researchers. But dissolution, reshaping and stabilization of the prevailing routine practices can be achieved in tool creation and implementation, and

providers are willing and able to produce solutions for the uncertainty and neglect in inter-organizational care. However, the adoption of the new tools and practices into general use did not succeed in the project.

The findings of the study contribute to the development of health care for multiple and chronic illnesses by identifying the current challenges and their possible solutions in the Finnish health care organization. Furthermore, the study provides insights about the processes of development in health care. The study identifies two complementary models for the development of health care in Finland. The *care package model*, which is based on productivity and process models adopted from engineering, and market values and *the model of negotiated care*, which is based on co-configuration, the public good, and care agreements. Contributions to boundary studies of organization, development, and change illustrate the enabling and restricting nature of boundaries. From the activity-theoretical perspective, the construction of an object is an essential aspect of giving sense and meaning to the processes of development, learning, and change in an inter-organizational activity. The limitations of the study and the research process are evaluated in terms of the reliability, validity, generalizability, utility and ethical dimension of the study.

Keywords: activity theory, border zone, boundaries, care of multiple and chronic illnesses, expansive learning, ethnography of change, change laboratory

Preface

Boundaries trigger the imagination and enable entering the unknown. The invisibility and surprises related to boundaries make them a fascinating research topic. Swimming across the historical border located on the sea as a child inspires my ideas about boundaries. My home was called the House of the Border Guards. However, it was not located near the outskirts of Finland but in the capital area of Helsinki. The border in question separated the area occupied by the Soviet Union from other parts of Finland after the Second World War until to 1956. However, in my childhood that boundary did not exist anymore. It had lost its concrete meaning but it still raised feelings of fear among the population. For me, a child, the border represented something mysterious that was difficult to understand since a concrete border could not be seen.

Later I learned that, theoretically, boundaries cannot be conceived on the basis of the opposition of presence and absence. ‘Différance,’ which according to Derrida is neither a word nor a concept, expresses some of their essence of not ‘being-present.’ Instead this ‘non-presence’ can be understood in traces of differences. For me this means that it is possible to get in touch with boundaries through exploring the multivoicedness and the history of boundaries. Since this study discusses a developmental project that is immersed in the life of chronic illness, the boundaries are explored in relation to action.

When characterizing experiences and interactions of the developmental project afterwards, the myth of Persephone seems suggestive: Just like Persephone, the daughter of Zeus and Demeter in ancient Greece, the researcher was obliged to spend half of her time in the Underworld, returning to earth again in the spring when the seeding time started (Spence, 1994, pp. 128–130). The idea of the myth is to capture the unarticulated and implicit phenomenon of fertility. Here, the myth tries to catch the unarticulated and invisible “seeds of development” in the collective activity of health care organization. The “Underworld” suggests the problems and tensions that are manifested in the care delivery of patients with a single or many long-term illnesses. “Returning to the earth” involves the process of “uncovering” the challenges in care provision.

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The developmental project *Developing a negotiated way of working between primary and specialized care in Helsinki* gave me an opportunity to meet many patients who gave their experiences, time and effort to the development of health care despite their illnesses. Without the insights provided by these patients, this study would not have been possible. I owe my sincerest thanks to them with wishes for improvements in future health care.

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Espoo and Lohja, August, 2006
Hannele Kerosuo

To Heikki, Miro, and Mona

1 Introduction

”A boundary is not that at which something stops but, as the Greeks recognized, the boundary is that from which something begins its presencing. That is why the concept is that of horismos, that is, the horizon, the boundary.”

(Anderson, 2004, p. 73/ Heidegger, 1975)

1.1 Boundaries, development, learning, and change

This study examines boundaries in health care organizations. Everyday life in health care organizations currently emerges as interwoven by multiple overlapping boundaries. Individual actors create and re-create these boundaries and are simultaneously affected by these boundaries.

Many of our conceptions of boundaries in everyday life are derived from the society and culture in which we live. We do not, however, pay attention to these boundaries when they correspond to our expectations of sense, meaning, and order in everyday life as well as in organizations and work. We take boundaries for granted until they become questionable in one way or another and ‘act against us.’ Therefore, boundaries are usually thought of as harmful; things to be avoided in everyday living. This study suggests, however, that boundaries can be important temporally and spatially emerging locations of change in organizations and at work. As traces of past activities and emerging futures, boundaries trigger learning and development.

I became interested in everyday obstacles while I was trying to change them as a planner in charge of training and development in an organization providing social and health care services on the primary level. Later, I became involved in an intervention that enhanced tools and practices for boundary crossing between primary and specialized health care for the care of patients with multiple and chronic illnesses (Engeström, Engeström & Kerosuo, 2001). During the project, I learned that the emergence of boundaries seems to coincide with increasing complexity in the work and organization of health care. The challenge of re-organizing the divi-

sion of labor among primary, secondary and tertiary care providers on a local level revealed various boundaries between professionals and organizational units.

The development of medical technology and treatments increases linkages among healthcare organizations and a growing market orientation adds to the complexity in health care (Plsek & Greenhalgh, 2001; Wilson & Holt, 2001). In particular, the care of patients who simultaneously have multiple, chronic illnesses or health problems appears to be complex (Davis, Wagner & Groves, 2000; Wagner, 2001; Wagner & Groves, 2002; Wilson and Holt, 2001). Multiple providers typically deliver the care, and patients are under the care of several specialists (Plsek & Greenhalgh, 2001). Coordination between multiple providers is made difficult by the boundaries between the primary and secondary care that bring bureaucratic and fiscal obstacles to each patient's care (Wright, Smeeth & Heath, 2003). In situations of care, a patient may be left 'in the middle,' 'in the no-man's land of care,' where no one takes overall responsibility for all aspects of the patient's care. For instance, the following excerpt from a specialist's interview illustrates such a situation.

Specialist: These organizations are unconnected to each other and a patient is at the boundary between these organizations and everything is not necessarily taken care of as it should be. (22.1.2001:133)

But what are these boundaries? How can the social, cultural, and organizational boundaries of everyday living be defined? Boundaries are necessary to human life. Without boundaries, everyday life would be impossible since boundaries structure the world around us. In the dictionary, a *boundary* is defined as "something (as a line, point, or plane) that indicates or fixes a limit or extent" (Merriam-Webster's Collegiate Dictionary, 1997, p. 135). A *boundary* is also "something that indicates bounds or limits; a limiting or bounding line" (Random House Compact Unabridged Dictionary, 1996, p. 247; see also OED <http://dictionary.oed.com>). Besides the formal definitions, the notion of boundaries points to differences and relational processes at work across a wide range of social phenomena, organizations, and institutions. A *boundary*, a *border*, and a *frontier* "share the sense of that which divides one entity or political unit from another," while *boundary* "in reference to a country, city, state, territory, or the like, most often designates a line on a map" (Random House Compact Unabridged Dictionary, 1996, p. 247). In figure 1.1, the white line covered with snow in the forest is an example of a boundary cut down in the forest indicating the northern section of the boundary between Finland and Russia.



Figure 1.1 The boundary cut down in the forest between Finland and Russia (Photo: Heikki Sarviaho, 2003)

The “line in the snow” denotes, however, more than a mere distinction between two countries (Malmberg, 2003). Besides representing social and cultural differences, national boundaries mediate distinctive differences due to their geopolitical location or history. For instance, the boundary in figure 1.1 is the eastern boundary of the EU, indicating a deep gap in standards of living in Europe (Malmberg, 2003).

Many disciplines and scientific approaches with differing ontologies and epistemologies are concerned with the social study of boundaries. In social sciences, boundaries are examined as “relational processes at work across a wide range of social phenomena, institutions, and locations” (Lamont & Molnár, 2002, p. 169). Lamont and Molnár make a distinction between *symbolic* and *social boundaries*. “Symbolic boundaries are conceptual distinctions made by social actors to categorize objects, people, practices, and even time and space. They are tools by which individuals and groups struggle over and come to agree upon definitions of reality... Social boundaries are objectified forms of social differences manifested in unequal access to and unequal distribution of resources (material and nonmaterial) and social opportunities” (Lamont & Molnár, 2002, p. 168).

Anthropological studies of border regions investigate boundaries as separating social forms, peoples, and regions (Alvarez, 1995, p. 448). Boundaries and peripheries are acknowledged as important temporal and spatial locations for change

(Lightfoot & Martinez, 1995). Life in the “borderlands” involves, however, struggle, tensions, and conflicts when attempts are made to cope with the boundaries (Alvarez, 1995; Rosaldo, 1993; Lightfoot & Martinez, 1995; Anderson, 2004).

Classical theories of organization and management define boundaries as coherent and object-like contours of an organization that are created to manage the complexities between an organization and its environment (Lawrence & Lorsch, 1967; Katz & Kahn, 1967). Current studies of organizational boundaries also investigate the social interactions and mental aspects of boundaries (Hernes, 2003, pp. 37–41). A boundary is considered both an enabling and constraining structure (Hernes 2003).¹ However, further empirical research is needed on organizational boundaries (Paulsen & Hernes, 2003). For instance, studies on dynamic shifts of boundaries across time and space are called for in organization studies (Heracleous, 2004, p. 100). Analyses of learning and development are also missing in organizational studies of boundaries.

In this study, I approach health care boundaries in the organization and practice of care for individual patients. Recent activity-theoretical studies on work and organizations provide resources for studying complex systems such as health care organization (Engeström, 2001; Engeström, 2000a; Engeström, Engeström & Vähäaho, 1999; Engeström, Engeström & Kärkkäinen, 1995). Cultural-historical activity theory represents a dialectical approach to the study of changing work practices in historically specific local contexts (Engeström, 1987). Cultural-historical activity theory makes an analytical distinction between durable collective activity systems on the one hand and temporally finite goal-oriented actions carried out by groups and individual subjects on the other (Engeström, 1987). Analogously, I investigate boundaries simultaneously as outcomes of social change at the ‘macro’ level and as involved in the boundary processes of development and learning at the ‘micro’ level of ‘boundaries-in-action.’

The purpose of the study is to contribute to studies of work, organization, and health care practice. In particular, the study discusses the opportunities for development, learning, and change in the organization of care for patients with multiple illnesses in Finland.

I define boundaries as established distinctions and differences between and within activity systems that are created and agreed on by groups and individual actors during a long period of time while they are involved in those activities. These distinctions and differences can be categorizations of material objects, people, and practices.

¹ By enabling and constraining properties of boundaries, Hernes (2003, pp. 41–42) refers to the discussion of structure in Giddens (1984, p. 169).

In the following sections, I will describe the development project that provides the research site of this study. In the project, the boundaries of the health care organization were crossed with the help of new communicative tools and practice that are explained in more detail in the next section. The activity-theoretical approach and the key concepts are presented in the subsequent section. After that, the research questions are formulated, and finally, the structure of the dissertation is presented.

1.2 Developmental project: Designing and experimenting with a new tool and practice for health care

I examine the experiences and interactions in complex research sites in a developmental project in which a new tool called a ‘care agreement’ and a new practice called ‘negotiated practice’ were implemented in the care of chronic patients with many illnesses in the capital area of Finland.² The care agreement tool with a corresponding new form of work called ‘knotworking’ was initially formulated and elaborated in an earlier project undertaken in children’s health care (Engeström, Engeström & Vähäaho, 1999; Saaren-Seppälä, 2004).

In the present project, the care agreement was constructed as a joint tool in negotiations between an adult internal medicine patient and his or her care providers. Additional tools, namely a care calendar and care map, were created and tested during the project. The care calendar depicts the history of the patients’ illnesses and care. The care map depicts the current care relationships, the information exchange between the different providers, as well as the division of care responsibility between them. The care agreement tool and the new negotiated practice enable the crossing of the organizational and practice boundaries in health care.

The patients of this study suffered from multiple illnesses, which were treated in various units on different levels of the health care organization in Helsinki. Altogether, twenty-six patients participated in the project. The participating internal medicine specialties were cardiology, endocrinology, pulmonary diseases, rheumatology, and renal diseases. In the intervention, the patients, the practitioners involved in their care, representatives of the health care management, and the

² A researcher group from the Center for Activity Theory and Developmental Work Research at the University of Helsinki conducted the project during the years 2000–2002. The members of the research group were Professor Yrjö Engeström, Senior Researcher Ritva Engeström, and the present author. My engagement with the project focused mainly on doing the fieldwork with the patients. Tarja Vähäaho (presently Tarja Saaren-Seppälä) was involved in the present project in 2000.

researchers elaborated on the new tool and the new practice while experimenting with them as part of the adopted implementation approach.

The Finnish health care system is divided into primary and specialized care.³ Primary care is carried out in health centers with general practitioners (personal physicians), each responsible for patients in a geographically defined area (population-based care). General practitioners provide the majority of care at primary care hospitals (health center hospitals), but there are also specialists practicing in larger primary care hospitals. Specialized care includes the levels of university, central, and regional hospitals in the hospital districts. Hospital care is carried out in divisions according to specialties and subspecialties. Besides hospital wards, there are also outpatient clinics. Ambulatory care is most often provided at primary care units, and the patient is referred to other levels of hospitals when needed. In ordinary cases, a general practitioner at a health center cares for patients who suffer from chronic illnesses such as diabetes and coronary disease. When needed, patients are referred to specialized care at hospital wards or outpatient clinics.

The health care system in the capital area of Finland has special features compared to other parts of the country, such as historically derived overlaps and divisions in the service structure of specialized care. In 2000, the primary care organization together with the hospital district representing the tertiary care initiated a rationalization process with the aim of removing the overlaps in specialized care. As a result of the rationalization, the secondary hospital care was mainly integrated into the municipally organized primary care while the hospital district provided the tertiary care. Along with the rationalization of services, the need also arose to develop new forms of collaboration between care providers in inter-organizational care. The project within which the data of this study was collected was aimed at developing the collaboration between primary and specialized care.

The project applied a special type of intervention method called a *Change Laboratory* (Engeström, Virkkunen, Helle, Pihlaja & Poikela, 1996). Drawing from activity theory and developmental work research, the Change Laboratory constitutes a work-based learning environment. The participants use the learning tools of the laboratory setting as resources while working on work-related problems.

³ Primary care includes care provided at health center clinics and general hospital care in health center hospitals. Specialized care includes secondary care provided at health center hospitals and tertiary care provided at university hospitals or central hospitals in Helsinki. In the articles, I have sometimes included tertiary care in my description of secondary care.

In this study, the video clips, patients' medical records, and other documents served as stimuli for learning and reflection on the development of the new practice and the new tools. The researchers edited the video clips from the research data that was gathered before the laboratory sessions. Altogether 19 sessions were organized, which included the discussion of 20 patient cases.

The project was carried out in two phases. During the first year of the project, problems in the patients' care provision were investigated by following the selected patients in the health care organization and by interviewing the patient and all of his or her providers. After the data gathering, a patient and his or her providers were invited to the Change Laboratory sessions. The patients and practitioners from two health centers, five health center hospitals, and three university hospitals participated in the Change Laboratory sessions. Altogether 108 persons participated, most of them only once.

In the second phase, a pilot group of thirteen medical doctors and three nurses applied the care calendar, the care map, and the care agreement to the care of selected patients. Altogether 39 persons participated in nine Change Laboratory sessions, including seven patients and one relative of a patient. A total of seven primary care physicians, five nurses and one manager participated as well as one secondary care nurse and two internists, and twelve tertiary care staff (seven specialists, two head nurses, and three nurses). Ten employees were invited collaborators and participated only once. The research group of three is also included in the number of 39 participants. During that phase, the researchers followed the professionals' application efforts. The first session was a preparatory gathering in which the process was negotiated with participants and the findings of the first phase of the project were presented. The eighth and the ninth session concluded the process and involved reflecting on the experiments with the new tools and the outline of a new model of work called 'negotiated knotworking.' 'Negotiated knotworking' is a new work practice that is intended to aid professionals in improving the care of chronically ill patients. The practical purpose of this study is to investigate patterns of illnesses and situations of care where the model of negotiated care can be applied.

1.3 The activity-theoretical approach and key concepts of the study

Inter-organizational care is a recently introduced form of organization in health care that is theoretically underdeveloped. This study draws on cultural-historical activity theory and ethnographic methodology to investigate the multi-organizational care of patients with multiple and chronic illnesses. In the project under study, this type of organization emerged as crosscut by boundaries in the collaborative practices of professionals.

The main concepts of the study are (1) the *object* carrying the collective motive of the activity, (2) the *activity* embedded in a multi-organizational field of activity systems, and (3) *contradiction* functioning as the driver of development, learning, and change. A historical perspective is emphasized throughout this study. Human activity is explored as collective, oriented towards an object, and mediated by artifacts in historically derived localities (Engeström, Miettinen & Punamäki, 1999). Boundaries are examined as historically established distinctions and differences in social practices and organizations that are contextually determined, interpretative, and hybrid. Activity-theoretical concepts are chosen because they clarify boundaries as outcomes of social change and the processes of changing them. It is the task of this study to investigate the dynamics of development, learning, and change as embedded in these boundaries and boundary crossings.

The first main concept of the study is the *object*. The concept of an activity involves a purposeful target called the ‘object’ that includes the collective motive for the activity (Leont’ev, 1978, p. 52). In cultural historical activity theory, the concept of ‘object’ has a specific meaning derived from German philosophy and the Russian language. The German concept of ‘Gegenstand’ captures the object’s embeddedness in activity as distinct from the notion of mere ‘Objekt,’ which refers to its materiality (Engeström & Escalante 1996, pp. 361–362). The ‘object’ is simultaneously “an independently existing, recalcitrant, material reality *and* a goal or purpose or idea that we have in mind” (Adler 2005, p. 404).

Objects separate activity systems from each other. For cultural-historical activity theory, the object of an activity is “both something given and something projected or anticipated” (Engeström, 1995a, p. 397). The object emerges when human needs and the material-cognitive formations of the world meet (Leont’ev, 1978, p. 54). In health care, the object and motive of an activity can be conceptualized in varying ways. From the viewpoint of a physician, an object of activity is a somatic disease or a symptom. The patient is the carrier and embodiment of the disease that represents the ‘raw material’ of the object. This ‘raw material’ needs to be transformed into a “meaningful pattern of important features, selected and arranged with the help of a more or less consciously used mediating model” (Engeström, 1990, p. 109). The meaningful pattern is used in the physician’s choice of examinations and therapeutic measures. For a patient, the ‘raw material’ takes the form of pain, a feeling of ill health, worry, and ailments. The patient also transforms his or her experiences into a meaningful pattern of symptoms by using culturally accumulated models that direct the actions of a patient upon the problem (Engeström, 1990, p. 109).

In health care organization, objects of care provision have traditionally been divided into care visits and care periods in hospitals. Problems in the continuity of care in chronic illnesses have led to the establishment of critical care pathways

carried out between primary and specialized hospital care. However, critical pathways only secure the linear and temporal construction of objects for one disease at a time while the horizontal and spatial dimensions in the care of multiple illnesses or diseases are represented and carried out with difficulty (Engeström, 2001, p. 144; Engeström, Engeström & Vähäaho, 1999; Engeström, Engeström & Kerosuo, 2003; Engeström, Puonti & Seppänen, 2003; Saaren-Seppälä, 2004).

In this study, the 'object' is first investigated in the pattern of multiple and chronic illnesses. This focus on the object reflects the level of a single patient's care. Secondly, the new work activity to be developed on the level of the health care organization is studied as a developmental object. Thirdly, the new care practice that the participating patients and professionals are learning is researched as an object of the learning activity.

The second main concept of the study is the concept of *activity*. The concept of activity and practice are distinct from each other in this study. According to Leont'ev's (1978, p. 63) three-level scheme, activity emerges as a threefold formation: (1) collective, object-oriented activity directed by motives; (2) actions directed by goals that actors have in terms of objects and collective motives; and (3) operations directed by the circumstances and tools at hand. These are conceptualized as "continuously proceeding transformations" between the three levels (Leont'ev, 1978, p. 67). Practice in this study refers to an intermediate level of activity between actions and activity. Practice is a recurrent pattern of activity that consists of strings of actions (Engeström, in press).⁴ Scribner and Cole (1981) studied the 'literary practices' of the Vai in Liberia. In their study, the term practice was used to describe certain conventional forms of reading and writing. For instance, letter writing involved repeated sets of actions that were culturally ordered among the Vai. In this study, the level of 'activity' is investigated as a multi-organizational field of health care activity while 'practice' is examined as a recurrent pattern of activity of treating patients.

Recent ethnographic approaches problematize the traditional conceptualization of the field. The ethnographic 'field' is not something to be discovered by and independent of the investigator. It is a world of infinite interconnections and overlapping contexts that needs to be constructed (Amit, 2000, p. 6). In activity theory, activity systems are included in contexts (Cole, 1996, p. 141) in which human agency constructs the activity systems simultaneously with the 'object-motive' of the activity and in relation to other elements of the activity (Leont'ev, 1981).

⁴ The concept of 'practice' here differs from other concepts of practice used in organizational studies of boundaries. For instance, the concept of 'practice' is 'a midlevel category' for Wenger (1998, pp. 124–125) that is "neither a specific, narrowly defined activity or interaction nor a broadly defined aggregate that is abstractly historical and social."

In activity theory, social and historical contexts such as organizations are conceptualized as activity systems (Engeström 1987). These involve elements of activity such as subjects, e.g., medical doctors focusing on an object, such as the care of a patient. The actions that emerge are mediated by the concepts and instruments applied in medical work practices. The object as well as the mediating artifacts are embedded in a community that is governed by specific rules and divisions of labor.

The focus of the study, i.e., the multi-organizational field of health care activity is depicted as activity systems in figure 1.2. It includes the activity system of primary and secondary care, the activity system of tertiary care, and the activity system of patients. The activity system of primary and secondary care is constituted of two intertwined activity systems that have distinctive historical origins. However, the changes in the organizational structure at the beginning of 2000 integrated primary and secondary care in the capital area of Finland.

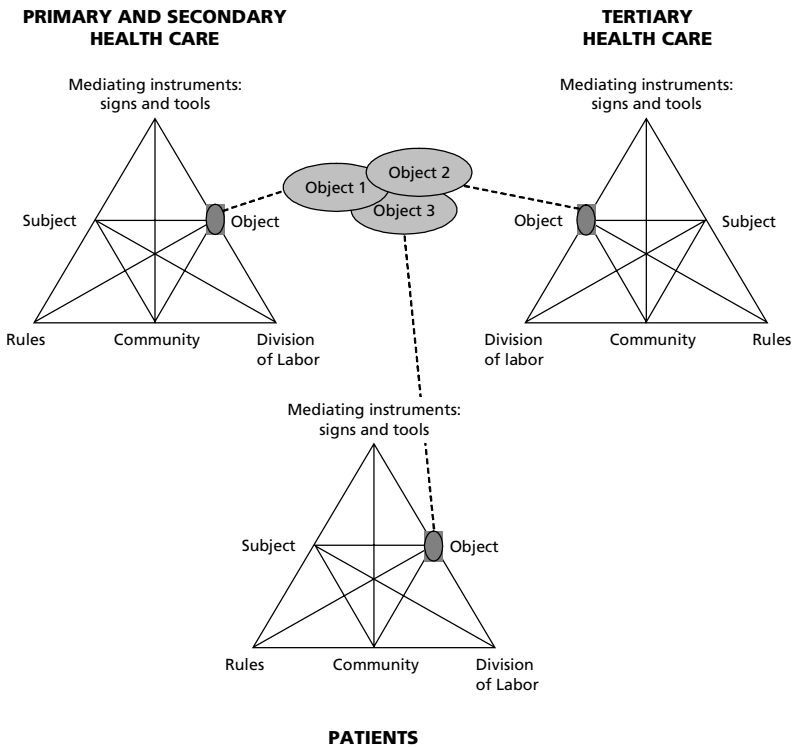


Figure 1.2 The multi-organizational field of health care activity as activity systems

In figure 1.2, the activity systems of primary and specialized care involve professionals whose actions are mediated by the ordinary tools of medical practice as well as the new tools (the care calendar, care map, and care agreement) developed and tested in the project. The actions of the professionals are directed by organizational rules, such as task descriptions, instructions, and timetables, and the division of labor between physicians, nurses, and other professionals in their community. The activity system of a patient encompasses actions that instantiate the patient's ordinary life-world. Patients, too, are engaged with tasks, instructions and timetables in the care of their illnesses. For instance, they have to remember to take their medicine and make changes in their diet.

The goal of this study is to examine the practical 'object,' the developmental 'object,' and the learning 'object' and their corresponding activity in the multi-organizational field of health care activity. The 'object' of an activity involves the collective motive of an activity. Focusing on activity theoretically defined objects of activity makes it possible to capture the complex processes of development, learning, and change of an activity in their entirety. First, the practical object, i.e., the pattern of multiple diseases and chronic illnesses, is investigated in a single patient's care provision. Secondly, the developmental object, i.e., the emerging new framework for treating multiple diseases and chronic illnesses, is studied in the developmental activity of implementing the new care agreement tool in the multi-organizational field of activity. Thirdly, the reflective object of the learning activity is explored in the process of the practitioners learning the new practice of negotiating and using care agreements.

The third main concept of the study is *contradiction*. In activity theory, contradictions are sources of development and change. "A contradiction is a historically accumulated dynamic tension between opposing forces in an activity system" (Engeström, 1999a, p. 178/Il'enkov, 1977). Engeström (1987, p. 89) presents four types of contradictions. Primary contradictions such as disturbances and tensions in ordinary work practices reveal a need state of development and change embedded in the present activity. Primary contradictions emerge within each element of the activity system. Secondary contradictions emerge between two elements of an activity system. Secondary contradictions often take the form of double binds in an activity. A double bind is an intense relationship that occurs when a human being receives two messages that contradict each other (Bateson, 1972, p. 208). Tertiary contradictions appear between the object/motive of the prevailing activity and the new activity that is being developed in resistance to the implementation of the new activity. Quaternary contradictions arise in parallel with the generalization of the new activity between the new activity and its neighboring activities. In order to be able to understand the contradictions and the 'why' of the present activity, e.g., the activity of the multi-organizational field of health care activity, it

is important to trace its historical development as well as the processes of development, learning, and change.

Development, learning, and change are fundamentally interconnected processes of transformation (Vygotsky, 1978, pp. 90–91), which, however, are sometimes difficult to distinguish from each other. Nevertheless, as Engeström (1987, pp. 144–157) illustrates, the possibility of development is embedded in learning processes and can be realized through expansive learning. Expansive learning involves productive experimentation in problem solving and tool creation. In expansive learning, learners make a conscious effort to reflect on their own activity, and through reflection they can break away from their predetermined contexts for action. Breaking away from the previous contexts of actions is not a simple act but contains a process of working out the internal contradictions of the activity.

Human beings carry out processes of expansive transformation in the zone of proximal development of activity. The zone of proximal development is “the distance between the present everyday actions of the individuals and the historically new form of societal activity that can be collectively generated as a solution to the double bind potentially embedded in the everyday actions” (Engeström, 1987, p. 174). The zone emerges, therefore, as a social interface of disturbances, struggle, and experimentation. Processes of struggle and experimentation can lead to expansive transformations. Yet not every zone of proximal development leads to expansive learning. Neither is development always to be understood as progression; it may also involve negative aspects, such as rebellion, deviation and marginality (Engeström, 1996). Expansive transformations involve engagement in tool creation and community formation, i.e., the modeling of a new activity. Therefore, from the activity-theoretical perspective, it is not enough to make interpretations or to uncover hybrid social realities, including the power implications involved in those realities. It is important to make a distinction between systemic tensions and asymmetric power relations, although power and domination are also at work in contradictions (Engeström, 1999a, p. 178).

In this study, the investigation of the zone of proximal development includes the search for the internal contradictions in their historical context as well as their manifestations in the present activity.

1.4 Research questions

This study focuses on the boundaries of health care organization and its practices in connection to their development, learning, and change in health care for patients with multiple and chronic illnesses. The care of these patients emerges as dispersed over several locations of the health care organization with many profes-

sionals in charge of the care. The concrete field of the study is the internal-medicine patient care, which takes place in two health centers, five primary-level hospitals including specialized care on the level of secondary care, and three university hospitals representing the tertiary level of specialized hospital care in Helsinki. Some private providers are also included in occupational health services. The organization of the primary and specialized health care activity is conceptualized as a multi-organizational field of activity systems where development, learning, and change are examined as embedded in the boundaries of organizations and practices of care. Boundaries delineate and frame the organizational forms and day-to-day practices in health care organization (Wright, Smeeth & Heath, 2003). However, further research on boundary dynamics and the processes of development, learning, and change is needed in organization studies (Heracleous, 2004; Paulsen & Hernes, 2003). Some activity-theoretical studies (Engeström & al., 1999; Engeström & al., 1995) demonstrate that boundaries between established organizational contexts and practices can be crossed in health care, which may indicate potentials for development, learning, and change. The general research question of the study is:

What are the boundary dynamics of development, learning, and change in health care for patients with multiple and chronic illnesses?

Multiple sets of boundaries are simultaneously in effect and may have an impact on the care of individual patients. From the perspective of improving the health care organization for multiple and chronic illnesses, it is important to know what kind of experiences patients have in connection to organizational and practice boundaries in their care. In a recent study, Frankel and Treger Hourigan (2004) pay attention to the small number of studies directly investigating patients' experiences of health care. Recent reviews of studies on patient illness experience demonstrate the meaning of illness for patients in terms of their personal history and subjectivity, coping actions, and strategies for managing everyday life (Pierret, 2003; Lawton, 2003). However, interrelations between subjective experiences, cultural factors, and social structure are not usually addressed in qualitative studies of patient experience and still need to be explored (Pierret, 2003, pp. 15–17). My first specific research question focuses on the multiplicity of boundaries in effect on a single patient's care as an experiential phenomenon:

1. How do individual patients experience boundaries in their health care?

The creation of boundaries should be explored in action instead of determining them as pre-existing entities (Abbot, 1995b). In studies of organizational boundaries, the research focus has shifted towards boundaries at the practice level (e.g.,

Paulsen & Hernes, 2003). However, the link between boundary studies and processes of learning is weak in organization studies (Holmqvist, 1999) and studies describing health care practice (e.g., Allen, 1997; Allen, 2000). The idea of the Change Laboratory method (Engeström & al., 1996) is to facilitate development, learning, and change through encounters between different actors, such as patients, healthcare professionals, and researchers. My second research question explores how boundaries are constituted and reconstituted in the social interaction that takes place in such an intervention.

2. *How are the boundaries of health care activity constructed and reconstructed in social interaction within a Change Laboratory intervention?*

The development, learning, and change of work practices require boundary crossing (Engeström, Engeström & Kärkkäinen, 1995). In the Change Laboratory, the emerging new activity of negotiated health care provision is created at the boundaries of the dispersed and fragmented activities of health care. The practitioners experiment with the new tools (the care calendar, care map, and care agreement) in the care of their patients. However, little is known of the dynamics of boundary crossing in the implementation of and experimentation with new tools and new practices. Thus, my third specific research question is:

3. *What are the dynamics of boundary crossing in the experimentation with the new tools and new practice?*

1.5 Structure of the dissertation

The dissertation consists of two examinable sections. The first section provides a contextualization and summary as well as a theoretical appraisal and legitimation of the second part. The second section consists of a series of articles previously published elsewhere. They provide the empirical data of the dissertation.

Our project of developing the care of patients with multiple illnesses began by following the patients, their illnesses, and their care trajectories, i.e., by ‘following the object’ in Helsinki. Therefore, chapter 2 starts with a review of literature on the conceptualizations of multiple and chronic illnesses and the organization of their care. The chapter demonstrates how the conceptualization of care organization for multiple and chronic illnesses is permeated by theories of modern medicine, sociology of health and illness, and disease management. Conceptualizing chronic illnesses and the care organization of chronic illnesses is multi-voiced, and some of the approaches exclude each other, as illustrated in this chapter. The literature

review enables me to position my study at the intersection of these multiple conceptualizations.

In chapter 3, I investigate the history of multiple chronic illnesses and health care organization in Finland. This chapter explores the rise of multiple and chronic illnesses as an object of care and the phases of development in Finnish health care, traces the formation of its boundaries, and sketches its hypothetical zone of proximal development. The historical analysis provides a sense of temporality for the analysis of the present-day boundaries. It helps me to locate the present organization of health care in terms of the past and the future.

In chapter 4, I review the literature and earlier studies on boundaries in work, organizations and health care practice and patient experience. These studies are presently moving from macro-level perceptions of boundaries being stable and unambiguous to perceptions that bring up the diversity and ambiguity of boundaries in practice. However, studies that focus on the processes of development and learning are still few. I discuss three approaches for studying boundaries in connection to development, learning, and change, and then I present a fourth approach that will serve as theoretical framework for investigating boundaries in this study. My framework suggests that boundaries are hybrid contexts of development, learning, and change in work and organizations. Yet boundaries provide potential for development and change while enabling expansive learning, during which the organizations can contribute to the creation of their possible futures.

In chapter 5, I will present the methodology of the study, i.e., the ethnography of multi-organizational field of activity. The ethnography of the multi-organizational field of activity makes connections and disjunctions between multiple locations of a patient's care simultaneously as it focuses on the processes of development, learning, and change of health care for patients with multiple and chronic illnesses. The fieldwork of the multi-organizational field of activity is constituted of the methods of following patients in dispersed locations of care. I will also lay out details of the data collected for the study and the methods as well as the proceedings of the data analysis in the published articles in chapter 5.

The central findings of the boundary dynamics of development, learning, and change in health care for patients with multiple and chronic illnesses are presented in chapter 6. The contributions and limitations of the study are discussed in chapter 7. The original publications, articles I–VI, are included after the eight chapters of the summary. In chapters 1–7, the articles are referred to using the Roman numbers listed after the table of contents. The articles that are connected to this research project but not included in the dissertation are listed at the end of this dissertation.

2 Perspectives of health care for multiple and chronic illnesses

2.1 Outlines for mapping the multi-disciplinary field of health care

This chapter examines the ‘theory-history’ of multiple and chronic illnesses and their care organization in previous studies. The theory-historical analysis examines the concepts and tools that mediate the conceptualizations of the object under focus, i.e., multiple and chronic illnesses (Engeström, 1987, pp. 325–326). The concept of ‘object’ is central to this activity theoretically grounded study and relates to all my research questions.

The theory-historical analysis of this research examines the multidisciplinary field of studies investigating multiple and chronic illnesses as well as the organization of their care. This chapter explores how multiple and chronic illnesses are conceptualized in biomedicine, sociology of health and illness, and disease management. Perceiving the different perspectives is important since they may have consequences in the organization and practices of care for multiple and chronic illnesses. For instance, see the implications of the diversification in the care practice of one patient (see article II, figure 3).

The term *chronic* denotes to disease or illness that persists for a long time (MedicineNet.com). The distinction between disease and illness refers to *disease* as a biological problem within an organism, while *illness* refers to the social experience and the consequences of having a disease (Weitz, 2001: 18). In this study, the term chronic illness is used to emphasize the social and experiential side of health problems and ailments in their social context.

Many of those with a chronic condition suffer from many chronic illnesses. This construction of illness and disease is often called ‘multiple morbidity’ (Wright, Smeeth & Heath, 2003) or ‘co-morbidity’ (Barendregt, Van Oortmarsen, Van Hout, Van Den Bosch & Bonneux, 1998; Wagner, 2001). The number of chronic illnesses is estimated to be increasing globally. At the same time, health

care providers are poorly equipped to manage chronic illnesses effectively, and many governments have difficulties coping with the escalating costs of health care (Epping-Jordan, Bengoa, Kawar & Sabaté, 2001).

The chapter is organized according to divergent perspectives in the organizational and social context of health care provision for chronic illness. However, the perspectives are not rigid but represent dynamic, partly overlapping views. As a matter of fact, various perspectives emerge in parallel in the field of providing care for multiple and chronic illnesses. Their co-existence is not always unproblematic, but it at times involves ‘credibility contests in science’ (Gieryn, 1999, p. 1). By credibility contest I refer to Gieryn’s idea of the contest over the ‘epistemic authority’ in a historically and culturally defined locality. Correspondingly, Starr (1982, p. 13) refers to contests of ‘cultural authority.’ According to Starr, ‘cultural authority’ is “the probability that particular definitions of reality...will prevail as valid and true” in a historical locality.

The knowledge of medical science about the diseased body and its curative processes is seen as authoritative. Various scholars in social sciences have challenged this dominant position since the 1960s by questioning the taken-for-granted realities, knowledge creation, and institutions in biomedical reality (Bury, 1986). As one critic points out, the object of medical science is not “the stable realities of the human body and disease” but “fabrications or inventions rather than discoveries” (Bury, 1986, p. 137). Or in other words, “claims to the discovery of disease are themselves social events and take place in social contexts” (Bury, 1986: 145).

The questions raised in this chapter are: (1) On what kind of developments and premises is the field of study based? (2) Who are the key agents in the development of health care provision? (3) What is the definition of a chronic health problem? (4) How is the health care provision organized? (5) What is a patient’s position and contribution to his or her care? (6) What kind of critique is presented of the perspective? First, the perspective of medical science is discussed. Second, studies focusing on the life-world of human beings with chronic illnesses are presented. Third, the field of managed care and disease management is explored.

2.2 The ‘golden age of medicine’ and the care of chronic diseases

The ‘golden age of medicine’ denotes the transformation of medical knowledge, practice, and policy that occurred during the last years of the nineteenth century and the first of the twentieth century (Brandt & Gardner, 2000). Because of its undeniable success, the biomedical approach became the official system of medicine in many countries and is presently publicly supported and financed in most countries (Bentsen, 2000).

Brandt and Gardner (2000, p. 21) maintain that the ‘golden age of medicine’ is usually associated with the impact of dramatic patterns of disease and human longevity. During this period, the germ theory of disease became the dominant trend in the study of diseases. Researchers identified microbes as a specific cause of many diseases and went on to develop therapeutic measures to destroy them in those who were infected. The metaphor ‘magic bullet’ represents the enormous impact of development among ‘microbe hunters,’ one of them being Ehrlich, who invented the medicine for the syphilis-causing *treponema* in 1909. The discoveries of other ‘wonder medicines’ such as penicillin, streptomycin, and other antibiotics marked the fulfillment of ‘magic bullet’ medicine. It ultimately extended beyond infectious disease into combating symptoms that could not be cured. For instance, medication for diabetes was generated out of the discovery of insulin (Brandt & Gardner, 2000).

In the 1970s, human populations experienced an ‘epidemiological transition’ from ‘the age of receding pandemics’ to ‘the age of degenerative and man-made diseases’ that were characteristic of industrialized societies. Contemporary medicine acknowledges that effective care provision for chronic illnesses is one of the major challenges in future health care (Davis, Wagner & Groves, 2000, p. 525). The ‘burden of chronic diseases’ is characterized as a global problem in all nations and is typical of all age groups in the world (Mascie-Taylor & Karim, 2003).

The biomedical definition of chronic conditions refers to a biological problem within an organism. Chronic disease is a morbid condition that involves symptoms, illness, and the impairment of a human organism (Weitz, 2001, pp. 18–20). A disease is, therefore, a deviation from the normal, specific, and universal, caused by unique biological forces and analogous to the breakdown of a machine, and it is defined and treated medically through a neutral, scientific process (Weitz, 2001, p. 125). Degenerative diseases such as diabetes, coronary artery disease, hypertension, and chronic obstructive pulmonary disease (COPD) are often pointed to as examples of chronic diseases (Wagner & Groves, 2002, p. 913).

Modern medicine is divided into general practice and specialties and sub-specialties. General practice focuses on human sickness on a general level, while specialties and sub-specialties focus on single diseases (Torpy, Lynn & Glass, 2003). The ‘golden age of medicine’ is often characterized as a period of the dramatic expansion of medical institutions in patient care, research, and medical education. Brandt and Gardner (2000, p. 28) represent the hospital as a ‘structural emblem’ of the ‘golden age’ that brought together the widest array of the technologies and achievements of the new medical science. “The problems of disease would be brought to the hospital to be isolated, identified, and when possible treated” (Brandt & Gardner, 2000, p. 28). Currently, clinical testing and evidence-based medicine are the ‘trademarks’ of a qualified biomedical practice. The accumula-

tion of specialized medical knowledge is a requirement for the optimal management of diseases. From the perspective of patients with multiple health problems, however, the trend towards specialization in medicine raises new needs for the integration of medical knowledge and more intense collaboration between providers than has previously been the case. Some practitioners in the field of medical science suggest that these patients could be provided for more effectively in general practice (Wright, Smeeth & Heath, 2003).

The developments in modern medicine also imply new expectations of the patient's involvement in clinical care. The relationship between providers and patients depended on the patients' compliance in following the doctor's orders and taking their medications (Vermeire, Hearnshaw, Van Royen & Denekens, 2001). Patients' compliance in their care is discussed in various studies, but the literature provides "little consistent information other than the fact that people do not always follow the doctor's orders" (Morris & Schulz, 1992, p. 295). Many scholars, in particular those involved in chronic illnesses, suggest more collaborative working relationships between doctors and patients (for instance, Holman and Lorig, 2000; Funnell & Anderson, 2000; Vermeire & al., 2001). As Funnell and Anderson (2000) maintain, physician-directed, compliance-oriented care is not an effective approach in the care of a self-managed disease such as diabetes.

In the latter half of the twentieth century, the modernist idea of disease expressed as the 'golden age' became the focus of growing challenges and critiques despite its victories in the cure of diseases. Some of these critiques suggested that a life 'free of disease' was a utopia (Brandt & Gardner, 2000), while others (Donaldson, 2000) claimed that other developments such as a higher standard of living, better housing, and nutrition resulted in the disappearance of infectious diseases instead of a 'magic bullet.' Other critiques representing the biopsychosocial model (Engel, 1977) and sociological and anthropological perspectives of disease, illness, and sickness (for instance, Strauss & Glaser, 1975; Strauss, 1984; Young, 1982; Bury, 1982) emphasized that while medicine was able to combat infectious diseases, it was not able to meet the challenges of chronic or incurable diseases. Chronically ill patients often have socio-economic factors, disabilities, and co-morbid conditions that make it more difficult for practitioners and the health care system to help them (Wagner, 2001, p. 945). However, despite the critiques, Brandt and Gardner (2000) assert that biomedical institutions and health care professionals have retained their power, respect, and high status. Many diseases that were before outside the reach of biomedical intervention are now targets of research in new searches for 'magic bullets' and other explanations such as the "'flaws' causing disease at the chromosomal level" (Brandt & Gardner, 2000, p. 34). In the following, I explore perspectives that meet the challenges of chronic illness as a social experience in time and space.

2.3 Life-course models and experiencing 'the burden of illness'

Life-course models focus on the patients' experiences of illness and the relationship between a sick person and his or her life context. Life-course models do not, however, represent a unified perspective on chronic illnesses and their care but a set of approaches interested in the illness experience in the social and cultural context. The purpose of these studies is to complement the biomedical perspective in the treatment of chronic illnesses—biomedicine in itself is considered indispensable.

Patients' experiences of illness and their involvement in their care are reconceptualized in life-course models. Patients are seen as active agents attempting to manage, mitigate, and adapt to their illness instead of being only victims of 'poor fate' or 'burdened by illness' (Bury, 1991). The focus on experience represents an interpretative approach to chronic conditions. However, reflections on the concept of organization are often missing in healthcare literature, as Davies (2003, p. 174) asserts: "A sociology struggling to be of and not in medicine achieved that result by becoming a sociology in organizations rather than of them."⁵

In life-course approaches, the concept of illness is separated from the concept of disease, although they are used in parallel. Engel's (1977) well-known biopsychosocial model of disease and illness emphasizes the understanding of social and psychological aspects of the illness process, while Young (1982) emphasizes the moral, social, and cultural definitions of disease and illness. Young (1982, p. 264) maintains that "disease refers to abnormalities in the structure and/or function of organs and organ systems; pathological states whether or not they are culturally recognized; the arena of biomedical model." Similarly, "illness refers to patient's perceptions and experiences of certain socially disvalued states, including, but not limited to, disease" (Young, 1982, p. 265).

Medical sociology of the chronic illness is, according to Bury (1982, pp. 168–169), based on two traditions;⁶ the functionalist approach to disease, illness and sickness in society, and the interactionist tradition focusing on empirical enquiry. A third tradition is introduced by Bury himself (1982) as an interpretative approach to chronic illness.⁷ According to the functionalist approach, health and illness are both organic and socio-cultural. Illness is characterized by dependency,

⁵ Yet, as also Davies (2003) maintains, the studies of Strauss et al. represent an exception in this realm.

⁶ As Bury (1982, p. 168) notes, the division into the two traditions simplifies the broad sociological discussion on the ideas of illness and disease in medical sociology (see, for instance, Gerhardt, 1989).

⁷ See Mishler (1984) for an interpretative approach emphasizing the views and positions of patients and physicians about their clinical encounters.

regression, and recovery, and there is a certain ‘sick role’ that an ill person adapts (Parsons, 1951). Ill people are also incapable of carrying out their other societal roles due to their illness. The sick role is usually adopted for a short period of time until a person becomes ‘cured.’ However, as chronic diseases are characterized by their long duration, they do not fit well into the Parsonian model of thought (Bury, 1997, pp. 86–87/Gallagher, 1976, p. 209).⁸

The second line in the medical sociology of chronic illness is the interactionist tradition (Bury, 1982, pp. 168–169). Having its origin in symbolic interactionism, the interactionist tradition bases the functioning of society on interactive social relationships and negotiations between participants of a social reality.⁹ Strauss and Glaser (1975) maintain that chronically ill people share many common problems that are complex by nature and need to be viewed in social and not simply in medical terms. However, in countries where the specialization of medicine is advanced, the organization of care “tends to be along the categorical lines” based on medical specialties rather than based on chronic conditions in general (Strauss & Glaser, 1975, p. 4). Life with a long-term disease requires the active participation of the patient in his or her care. Furthermore, chronic illnesses require new abilities such as reading the signs of grave medical crises, controlling symptoms, and learning the regimens. These new abilities include the constant monitoring of symptoms such as pain, dizziness, or trembling. The nature and degree of the symptoms gives direction to how much the symptoms of an illness interfere with the life of a sick person and his or her social relationships (Strauss, Fagerhaugh, Suczek & Wiener, 1997/1984).

In the interactionist tradition, Strauss and his colleagues investigate what ‘living’ with a chronic illness means (see, for instance, Strauss & Glaser, 1975; Strauss, 1984; Strauss & al., 1997/1984). The course of a disease from the perspective of an ill person is studied as an ‘illness trajectory’ (Strauss & Glaser, 1975, p. 47). The pattern of a trajectory consists of deterioration, recovery, and stable phases of illness, but each type of chronic illness or sub-type may have its own distinctive characteristics. The illness trajectories may be predictable or uncertain depending on the type of illness. In order to come to terms with an illness, a sick person has to be aware of the course or the ‘trajectory’ of the illness. The focus on trajectories also involves the work and organization of medical care (Strauss & al., 1997/1984). Wiener, Fagerhaugh, Strauss and Suczek (1984, p.15) define trajectories as including “not just the physical course of illness but all the work that patients, staff, and

⁸ In his later essay, Parsons agrees that the theory of the sick role may not fully meet the circumstances of a chronic illness, but he still considers the patients’ compliance to regimens as a key element of maintaining the sick role (Bury, 1997, p. 86/Parsons 1978, p.18).

⁹ See Gerhardt, 1989, pp. 157–177 for a more profound discussion.

kin do to deal with the illness, and all the social/psychological consequences that encircle the illness course (its intrusiveness on relationships, temperament, and so forth.”

The organization of care for chronic conditions should overcome the home-facility dichotomy according to which the patient is responsible for coping with chronic conditions at home, while the personnel is responsible for the treatment of the conditions at the facilities of health care (Strauss & Glaser, 1975, p. 134). This means that patients ought to have more say in decisions on their care at the hospitals and that the health care should be extended into the patients' home environment. In order to complete these challenges, the personnel need to increase their accountability for everyday matters at the facility and to become aware of the patients' multiple biographies including their biographical experiences with medical and health care and their personal histories of encounters with relatives, friends and acquaintances (Strauss & Glaser, 1975, pp.134–139). The patient's efforts to participate in managing and shaping their own illness trajectories should also be acknowledged as part of the care work (Strauss & al., 1997/1984). Strauss (1984) and his colleagues bring up various social situations, organizational conditions, and practices in which “medicine fails” to meet the expectations of sick people. For instance, community hospitals run according to the needs of the medical schools or professional requirements, not according to local needs (Nanry & Nanry, 1984).

The third tradition in life-course approaches increases the general understanding of the chronic illness experience. This interpretative tradition of medical sociology introduced by Bury (1982) captures ‘the taken-for-granted assumptions and behaviors’ challenged at the onset of a chronic illness that represent a ‘biographical disruption’ in the life of an ill person. Bury maintains “that illness, and especially chronic illness, is precisely that kind of experience where the structures of everyday life and the form of knowledge which underpin them are disrupted” (Bury, 1982, p. 169). Bury (1982, p. 179) suggests that medicine should also be approached “as a cultural system, as both an important resource for people in times of distress and pain and as a constraint in their search for the deeper meaning of experience.” The professional knowledge of chronic diseases is valued among patients since it provides an “objective fixed point on a terrain of uncertainty” (Bury, 1982, p. 179). However, it is recognized that professional and lay worlds appear to be separate and bring discontinuity to the care delivery for chronic conditions. Professional knowledge is limited and needs to be supplemented by knowledge from the patients' life-worlds and biographies (see, also Mishler, 1984; Hydén & Mishler, 1999). For instance, narratives represent a form of knowledge that enables presentating, discussing, and negotiating illness from the perspective of a patient's life world (Hydén, 1997).

Charmaz (1983) deepened the understanding of suffering in chronic illness by examining how social situations and relationships shape a person's self-identity during the course of a chronic illness. Drawing from symbolic interactionism, Charmaz approaches the chronic-illness experience as a social psychological process of 'losing one's previous self.' In a person's inner dialogue, his or her previous self is questioned during the course of the illness. In her findings, Charmaz shows that ill people rely on others for their reflections on self during their illness. Paradoxically, their relationships to others often weaken, and social isolation increases during the course of an illness.

Williams (1984) focuses on later phases of illness in the lives of chronic patients in order to study people's beliefs about the etiology of their illness and how they make sense of their illness. Williams approaches patients as social and historical agents with a biographical identity trying to establish "points of reference between body, self and society and to reconstruct a sense of order from the fragmentation produced by chronic illness" (Williams, 1984, p. 177). Williams reports three types of beliefs about the genesis of a chronic illness. In the first place, a chronic illness may be seen as deriving from the connections between work and illness, and the believed cause of the illness is more or less political. Secondly, a chronic illness may express a social psychological relationship between the body and the self, and moreover, the self's relationship with the world. Thirdly, a chronic illness may be believed to have appeared through transcendental causation and carry a moral or religious explanation.

In medical anthropology Kleinman and his colleagues explore the personal experience of illness as a social, and in particular, a culture-bound experience (Kleinman & Seeman, 2000). This approach involves a more responsive understanding of the subjective 'somato-moral' experience, which captures those issues of illness that are 'at stake' for an individual at the onset of an illness. In his model of the personal illness experience, Kleinman (1997) integrates cultural representations, i.e., the collective pattern of meanings, collective experiences, i.e., the events and social processes defining the lives of entire generations of people, and subjectivity. These aspects of an illness experience emerge in the reciprocal influences that constitute a personal experience of illness. The socially and culturally bound experience of illness places the idea of an illness experience in broad social contexts. Thorne (1993) approaches experiences of chronic illnesses in broader contexts that involve interpersonal and institutional levels of health care. These experiences depict the 'journey into health care' for the chronically ill and their families as "an odyssey of rules, regulations, and policies that make little sense and provide little obvious benefit to anyone." From the patients' and their intimates' point of view, "the system makes obtaining health care extremely complex and, at times, almost impossible" (Thorne, 1993, p. 146; see also Gillick, 1995).

Recently, politics, power, and knowledge are issues raised by the postmodernist agenda in health care. The poststructuralist theory of health elaborated by Fox (1993) builds on the critique of the modernist position of sociology of health and healing. In particular, the poststructuralist theory of health differs from much of sociology of health and illness in its concern for power, language, and knowledge as characteristics of the 'politics of health talk.' In the politics of health talk, the discursive formation of health is explored as 'small designs' and local meanings instead of 'grand design.' Health as well as the subjects are constituted through discourse, knowledge, and power. Fox's elaboration leans on Foucault's argument that the ability to control knowledge and meaning is achieved through disciplinary and professional powers in institutions. The inscription of the medical and social discourse refers to the 'writing of the body,' e.g., on the 'non-organic body-without-Organs.' 'Body-without-Organs' (BwO), as Fox terms, is a *political surface*, with real properties that must be explored. But it is not knowable in the sense that the medical body is 'knowable' (Fox, 1993, p. 38). The outcome of the inscription is what Fox calls 'arche health.'¹⁰ The concept of 'arche health' involves not one specific definition of health, but a "fragmented, multivocal, disseminated manifestation of desire" (Fox, 1993, p. 44). The poststructuralist theory of health has been criticized for not meeting the practical ends of medical sociology (Hetherington 1995, p. 420), rejecting the modernist sociology of health "in favor of some abstract philosophical and psychoanalytic formulations, with an over-emphasis on language, particularly when discussing power."

Qualitative studies of patient experience represent a conceptual shift from the 'outsider perspective' represented by the Parsonian concept of the 'sick role' to an 'insider perspective' of the patients' subjective world of illness and disease (Conrad, 1990; see also Lawton 2003).¹¹ Life-course models have increased the understanding of the meaning of chronic illness for patients in terms of their personal history and subjectivity, coping actions and strategies for managing everyday life, and social structure (Pierret, 2003; Lawton, 2003). 'Biographical disruption' serves as a useful concept in the analysis of the nature of chronic illness and its coping processes, practical strategies, and the symbolic styles of adjustment it

¹⁰ Fox calls the poststructuralist concept of health 'arche health' in homage to Derrida's (1976, p. 56) notion of 'arche writing,' which he developed in his discussion of 'différance.' 'Arche writing,' argues Derrida, is that which supplies the possibility of writing — based on a system of difference. When applied to the concept of health, 'arche-health' is, according to Fox, that which refuses to be discursive (Fox, 1993, pp. 139–140). 'Arche health' is intertextual; 'différance' is that which differs and is 'deferred.'

¹¹ Recent discussions also stress the importance of patients' illness experiences in studies of illness as well as in health care provision in Finland. See, for instance, Honkasalo, Kangas & Seppälä (2003).

calls forth, but the model is adult centered, missing the disruptions of the aged and those with congenital abnormalities (Williams, 2000). By stressing caring relationships, interaction, and support, life-course models do not, however, usually deal with the organizational structure of health care (Griffiths, 2003; Pierret, 2003). Future studies could also benefit, as Griffith (2003, p. 165) suggests, “from the exploration of linkages (formal and informal) between levels of health care organization.”

2.4 Disease management — the ‘best value’ for money in the provision of chronic illnesses

Since the early 1990s, disease management has been introduced as a way to provide cost-effective and good-quality care (Hunter & Fairfield, 1997). Kesteloot (1999, p. 509) describes disease management as an approach that provides the ‘best value’ for money. The term disease management was first used in the 1980s at the Mayo Clinic in the US (Kesteloot, 1999). Disease management was initiated in the mid-1990s in the US by pharmaceutical companies, which began to offer educational services to patients using medication for chronic diseases (Bodenheimer, 2000). By 1999 about 2000 companies had established disease management programs for illnesses such as diabetes, asthma, and congestive heart failure (Bodenheimer, 2000). In the recent past, disease management has become widely adopted in health services with a variety of definitions and component interventions (Norris & al., 2003).

Disease management is defined in many ways depending on the focus or purpose of its application, the author’s perspective, and the delivery system to which the term is applied, whether it is primary services, specialty-based services, or pharmacy services (Norris & al., 2003). Zitter (1997, p. 4) defines disease management as “a comprehensive, integrated approach to care and reimbursement based on a disease’s natural course.” Elrodt & al. (1997) describe disease management to be an approach that coordinates medical resources across the health care delivery system. Norris & al. (2003) integrate chronic disease management and evidence-based care in order to maximize health outcomes in populations as well as for individuals. Chronic disease management is “an organized, proactive, multi-component, patient-centered approach to healthcare delivery that involves all members of a defined population (e.g. provider panel or health plan) who have a specific chronic disease, or a subpopulation with specific characteristics” (Norris & al., 2003, p. 479). The goal of chronic disease management is to improve short- and long-term health. The economic outcomes in a specified population with the disease also act as a target of disease management.

From the perspective of chronic illness, each chronic illness — asthma, diabetes, arthritis — is no longer approached in isolation in disease management, but similar strategies are considered to be equally effective for a variety of chronic diseases (Davis, Wagner & Groves, 2000). In many cases, the focus of disease management is on multiple chronic diseases or co-morbidities (Wagner, 2001). Even so, evidence about the natural course of single diseases and their diagnosis, treatments, and regimens defines the knowledge base adopted in disease management (Hunter & Fairfield, 1997). Chronic diseases are usually recognized to be uncertainties, requiring continuous and complex management. The goal of treating chronic diseases is not only to cure but to maintain a pleasurable and independent life. The most 'suitable' diseases for chronic disease management include those that are complex, common, or difficult and costly to manage (Norris & al., 2003). Thus, the most common diseases in disease management are diabetes, heart failure, asthma, hypertension, cancer, and depression. Other potential conditions are arthritis, pain, HIV/AIDS, and chronic obstructive pulmonary disease (COPD). However, the data on the outcomes of these applications is limited (Norris & al., 2003).

Disease management has been implemented into varying use starting from the health promotion, patient education, and training for self-care introduced by the pharmacy companies to hospital interventions, component models, population-based models, and programs making use of multiple approaches (Zitter, 1997; Hunter & Fairfield, 1997; Norris & al., 2003). Eichert, Wong, and Smith (1997) suggest that a successful implementation of disease management requires a match between systems thinking and the structure, skills, and culture of each organization in the health care system. Disease management programs involve clinical practice guidelines, treatment algorithms, critical or integrated care pathways, or combinations of various applications (Zitter, 1997; Campbell, Hotchkiss, Bradshaw & Porteous, 1998). Clinical practice guidelines define optimal practices for efficient health care provision (Kelly & Bernard, 1997). Critical care pathways "are care plans that detail the essential steps in patient care with a view to describing the expected progress of the patient" (Campbell & al., 1998, p. 133). However, few evaluations have been done of the cost of developing and implementing integrated care pathways and their effectiveness in changing practices and improving outcomes (Renholm, Leino-Kilpi & Suominen, 2002; Pinder, Petchey, Shaw & Carter, 2005; Bodenheimer, 2000).

Contrary to the programs presented above, Bodenheimer, Wagner, and Grumbach (2002) suggest a Chronic Care Model as a multidimensional solution to the complex problem of chronic diseases. The chronic care model constitutes a major rethinking of primary care practice, in which chronic care takes place within three galaxies: (1) the entire community, (2) the health care system, and (3) the

provider organization. Within this trigalactic universe, the essential elements are community resources and policies, the health care organization, self-management support for patients, delivery system design, decision support provided by an evidence-based clinical practice, and a clinical information system including practical solutions such as a reminder system for primary care teams about practice guidelines, a feedback system for physicians, and registers for planning individual patient care and conducting population-based care. The chronic care model has been implemented in a variety of practice organizations in the US, and it is currently being evaluated for the NHS in the UK (Wagner, 2004; Lewis & Dixon, 2004).

What is a patient's position and contribution to his or her care in disease management and managed care? The increasingly complex nature of diseases and comorbidities as well as complicated drug regimens increase patients' contributions to their own care as a necessary element of achieving the best possible outcomes (Wagner, 2001, p. 945). In order to fulfill the tasks of patient involvement, disease management applies patient management tools such as self-care, empowerment, health education, and compliance enhancement (Kesteloot, 1999, p. 509). Actually, in some care processes effective care means involving patients as partners in their care (Holman & Lorig, 2000; Davis & al., 2000) or even as principal caregivers (Bodenheimer & al., 2002). However, as Holman and Lorig (2000) maintain, the reforms deriving from the industrial model in managed care which view healthcare as a production process and the patient as a customer lead easily to the exclusion of patients from the health care process.

Hunter (2000) considers the principles of disease management important to the redesign of health care service, especially because of the greater attention to prevention and primary care. Hunter views disease management as well suited to the provision of chronic conditions, but he pays attention to the lack of evidence for cost savings and improved practical outcomes in patient care (see also Kesteloot, 1999). Kesteloot considers disease management programs to be difficult to implement since they involve behavioral changes that are hard to achieve. Disease management also 'erodes' the clinical autonomy of medical professionals while accountability for their work increases. The lack of integrated information systems is also, according to Kesteloot, an important barrier. There is a danger that short-term objectives are overemphasized in commercialized health care. Particularly in the US, where private companies run disease management programs, the actual caregiving may be in danger when companies focus on the enhancement of profits (Bodenheimer, 2000).

The fragmentation of services raises questions about who should receive the responsibility for coordinating care. While appearing as an essentially disease-specific approach of health care provision, Kesteloot (1999) argues that disease

management may disrupt the continuity of care toward individual patients with multiple disorders. Lewis and Dixon (2004) claim as well that disease management does not acknowledge the importance of developing a generic model for managing multiple chronic diseases. Evidence-based medicine, clinical effectiveness, and performance indicators also fail to recognize elderly people with multiple impairments and long-term diseases (Carpenter, Bernabei, Hirdes, Mor & Steel, 2000), and therefore, the provision of care for the increasing elderly population remains unsolved.

2.5 Perspectives of health care organization and the challenge of multiple health problems

Table 2.1 summarizes the perspectives of health care organization in terms of developments and premises, major players, the definitions of chronic health problems, the patients' contribution, and the critiques on the perspectives.

Table 2.1 Perspectives of health care organization for multiple and chronic illnesses

Question	Biomedicine	Life-course models	Disease Management
1. On what kinds of developments and premises is the field of study based?	Specialization of medical knowledge, invention of new medications and treatments	Patient illness experience in its social, organizational and cultural contexts and relationships	A comprehensive and integrated approach to cost-effective and good quality care
2. Who are the key agents in the development of health care provision?	Medical scientists and practitioners	Social scientists (and patients)	Organizers, representatives of management, and medical practitioners
3. What is the definition of a chronic health problem?	A biomedical problem within an organism	Disease is a pathological state in the function of organs, while illness a socially disvalued state experienced by patients	Single diseases defined by medicine
4. How is the health care provision organized?	Clinical and hospital care in primary and secondary care	Emphasis on caring relationships, interaction, and patient support	Industrial models applied together with evidence-based practices, clinical practice guidelines, and critical care pathways
5. What is a patient's position and contribution to his or her care?	Physician-directed, compliance-oriented care	Patients' experiences and subjectivity need to be considered in their health care	Patient management tools: self-care, empowerment, health education, and compliance enhancement
6. What kind of critique is presented of the perspective?	Biomedicine cannot meet all the challenges of chronic diseases	The organizational structure of health care is not considered	Lack of evidence showing cost savings and improved practical outcomes in patient care

The perspectives of the three approaches that are presented in table 2.1 have some overlaps and differences. The development of biomedicine is based on the specialization of medical knowledge and the invention of new medications and treatments (Brandt & Gardner, 2000). Life-course models of the sociology of health and illness attempt to increase the understanding of patient illness experiences in their social, organizational and cultural contexts and relationships (Bury, 1997). Disease management enhances cost-effective and good quality care (Hunter & Fairfield, 1997; Kesteloot, 1999).

The developers of health care include medical scientists and practitioners in biomedicine, social scientists in sociology of health and illness, and organizers, representatives of management, and medical doctors in disease management. Biomedicine and disease management share a disease orientation to health care provision, while sociology of health and illness complements the biomedical perspective in the treatment of chronic illnesses (Hunter & Fairfield, 1997; Wagner & Groves, 2002).

All three perspectives focus on the health care provision organized into clinical and hospital care that is carried out in primary care and specialized care. However, sociology of health and illness emphasizes caring relationships, interaction, and patient support in clinics, hospitals, and patients' home environments (Griffiths, 2003; Pierret, 2003; Strauss & al., 1997/1984), while disease management has adopted industrial models that are applied together with evidence-based medicine, clinical practice guidelines, and critical care pathways (Kelly & Bernard, 1997; Campbell & al., 1998; Bodenheimer & al., 2002; Norris & al., 2003).

A patient's position and contribution to his or her care is based on physician directed and compliance oriented care in biomedicine (Funnell & Anderson, 2000; Vermeire & al., 2001), while sociology of health and illness is also concerned with patients' experiences and subjectivity in health care (Pierret, 2003; Lawton, 2003). Disease management is also physician-directed and compliance-oriented, but it has adopted patient-management tools such as self-care, empowerment, health education, and compliance enhancement in health care (Kesteloot, 1999).

Previous studies show that health care provision is well equipped to treat single and clearly defined diseases with medications and treatments based on clinical evidence. The critique of biomedicine is, however, concerned about biomedicine not being able to meet all the challenges in the provision of chronic diseases. For instance, aspects related to the patients' home environment (Donaldson, 2000), socio-economic factors, disabilities, and co-morbid conditions cannot be helped (Wagner, 2001).

Qualitative health research provides useful analytical tools for understanding and interpreting the experiences of severely ill people suffering from chronic illnesses, but sociology of health and illness does not usually deal with the organizational aspects of health care (Davies, 2003; Griffiths, 2003; Pierret, 2003).

Disease management provides comprehensive and integrated approaches to the organization of health care provision, but disease management lacks evidence of cost savings and outcomes of good quality care (Hunter, 2000; Kesteloot, 1999). Disease management is described as a patient-centered approach since it is expected to improve outcomes for patients (Hunter & Fairfield, 1997; Kesteloot, 1999), but the focus may often be more on the cost savings than on good outcomes for patients (Norris & al., 2003).

Recently, the care of multiple and chronic illnesses is also considered to be becoming more complex than before, causing difficulties for effective provision (Goldberg, 1996; Davis & al., 2000; Wagner, 2001; Wagner & Groves, 2002; Wilson & Holt, 2001). Complexity is an inherent essence of biological and social systems in that few if any human illnesses can be said to have a single cause or cure (Wilson & Holt, 2001, p. 685). Today's epidemics have "fuzzier boundaries," and "they are the result of the interplay of genetic disposition, environmental context, and lifestyle choices" (Plsek & Greenhalgh, 2001, p. 625).

Health care organizations are complex in that they constitute multiple self-adjusting and interacting systems (Plsek & Greenhalgh 2001). The development of medical technology and treatments increases the complexity of health care since, for instance, the ideal drug treatments for chronic diseases become more complicated every day (Wagner & Groves, 2002). The most challenging are the treatments for multiple illnesses that involve the need to balance the illnesses and their regimens. For instance, the control of glucose levels in diabetes requires many arrangements and check-ups that are complex to manage in patients' day-to-day control of their blood glucose (Wilson & Holt, 2001). Furthermore, the provision of multiple illnesses involves several types of work, causes complexities in the division of labor, and raises confusion over the coordination of care (Strauss & al., 1997/1984, pp. 11–19).

The challenge of complexity in health care requires a new way of knowing. Plsek and Greenhalgh (2001) suggest that the science of adaptive systems provides important concepts and tools for tackling the present challenges in health care. These involve the exploration of new possibilities through experimentation and autonomy and working at the edge of knowledge and experience. The 'edge of chaos' is a zone involving "insufficient agreement and certainty to make the choice of the next step (obvious as it is in simple linear systems), but not so much disagreement and uncertainty that the system is thrown into chaos" (Plsek & Greenhalgh, 2001: 627/Stacey, 1996). The 'complex zone' is very close to the idea of the zone of proximal development in cultural-historical activity theory, which is presented in section 1.3.

The complex adaptive systems are described as having fuzzy rather than rigid boundaries, and they are embedded within other systems with which their evolution is intertwined. The 'certainty-agreement diagram' based on Stacey (1996)

depicts the relationships between a simple system, a complex zone, and chaos. Plsek and Greenhalg (2001) use a diagram to represent the challenge of complexity in current health care. The development and application of clinical guidelines, the care of a patient with multiple clinical and social needs, and the cooperation of educational and development initiatives throughout a practice or department are issues they name as lying in the zone of complexity.

Figure 2.1 represents the ‘certainty-agreement diagram’ (Plsek & Greenhalg, 2001, p. 627/Stacey, 1996). In this study, I use the diagram to summarize the challenges of developing the object of care, e.g., multiple and chronic illnesses, and its provision in the reviewed studies. These challenges are explored and discussed further throughout this study.

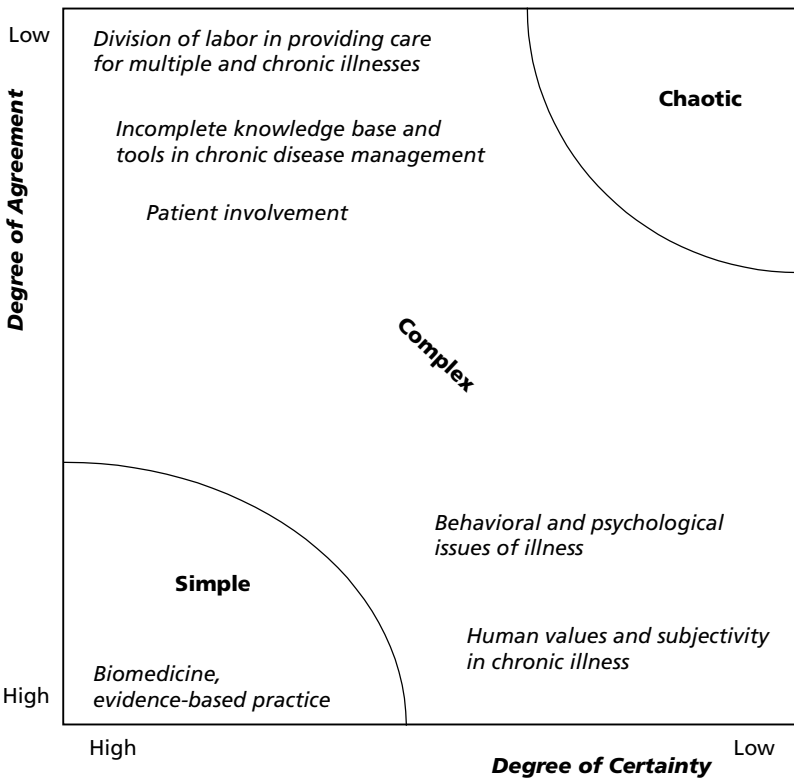


Figure 2.1 The complex zone of the challenges in health care organization for multiple illnesses (adapted from Plsek & Greenhalg, 2001, p. 627)

Biomedicine, the biomedical model of diseases, and evidence-based medical practice are situated in the simple zone since their conceptualization of disease and their treatments are generally agreed upon and claimed as certainties in the health

care field (Brandt & Gardner, 2000; Muir-Gray, 1999). The evidence may, however, sometimes be imprecise, equivocal, or conflicting (Plsek & Greenhalgh, 2001, p. 625). But the practical domains of medicine still stick to previous concepts and practices, although a change towards a more holistic concept of health has occurred in academic and institutional contexts (Alonso, 2004).

The increasing necessity of involving patients in the self-care of chronic diseases, however, brings along aspects of complexity to the care practice and processes of these patients, which may be considered as lying in the complex zone (Holman & Lorig, 2000; Wagner, 2001; Wright & al., 2003). Oliver (1998) questions the positivist health care research on its own tenets of objectivity from the perspective of disabled people as participants in their own care. Although it is generally accepted that subjective experiences can be studied objectively, positivist studies refuse, according to Oliver, to involve subjects for fear of bias. Oliver maintains, “[s]cientific researchers often use the words ‘suffering’ and ‘victim’ as if they are accurate descriptions and not untested, biased assumptions which many disabled people do not experience” (Oliver, 1998, p. 1447). From the perspective of this study, positivist research may also be in trouble when aspects of subjectivity need to be focused on in health care for multiple and chronic illnesses.

The economic aspects of disease management are situated in the complex zone. For instance, Hunter and Fairfield (1997) notice that the weakness of disease management lies in its incomplete knowledge base, which raises questions related to the complex zone. Chronic disease management may also involve interventions addressing behavioral and psychological issues of illness, such as patient education, that extend beyond the traditional biomedical model (Norris & al., 2003, p. 482). The adoption of ‘managed care’ in Great Britain and Continental Europe is an example of such developments (Huw, Latimer & May, 2003). The redistribution of medical work between professionals, policy makers, and health managers leads to complex and frequently conflicting sets of agendas characteristic of the complex zone. In order to settle the complexity, practitioners produce hierarchies of appropriateness — of work, patients, and personnel — that, in turn, produce a new distribution of medical work, and finally, a new kind of primary care organization (Huw & al., 2003).

Activity-theoretically based developmental work research has investigated development, learning, and change in health care since the 1980s.¹² Cultural-historical activity theory contributes to the challenges emerging in the complex zone of health

¹² The first research project ‘Levike’ studied the work of health center physicians (Engeström & al., 1988). Among the various publications on health care see, for instance, Engeström (1990; 1995a; 2001), Engeström & al. (1999; 2003), R. Engeström (1999a; 1999b), and Saaren-Seppälä (2004).

care organization (figure 2.1) by providing a theoretically based approach for studying development, learning, and change in human activity (Engeström, 1987).

The primary motive of development, learning, and change is the object of activity that is somehow contradictory and questioned by the practitioners of an activity. The meaningfulness of the object, i.e., the collective motive included in the object, provides sense and meaning for the individual actions in an activity. Objects of activity are embedded in social relationships (Miettinen, 2005, p. 58). These relationships need to be functionally coordinated in order to be able to create coherence and stability for the object (Miettinen, 2005, p. 60). In developmental activity, the expansion of the object leads to a reconstitution of social relationships. This means that the entire new activity becomes the object of development with related practices.

In health care, the construction of the object, i.e., the disease, illness, or a symptom is embedded in multiple societal, organizational, and professional relationships. But, as the literature presented in this chapter suggests, the different conceptualizations of chronic illnesses and the organization of their care is multi-voiced, while some of the approaches exclude each other by creating boundaries between the representatives of different approaches. The certainty-agreement diagram in figure 2.1 summarizes some of the features that are reported to have a low degree of agreement and certainty and, therefore, emerge in the 'complex zone.' These features involve the implications of patient involvement, an incomplete knowledge base, and tools in chronic disease management that lack a high degree of agreement. The acknowledgement of human values and subjectivity in chronic illnesses, behavioral and psychological issues related to illnesses, and the division of labor have a low degree of certainty in the care provision for multiple and chronic illnesses. From the activity-theoretical perspective, dysfunctions and disturbances emerging in social relationships can also act as a driving force for the development, learning, and change of activity in the zone of proximal development. In this study, the complex zone is, therefore, extended to represent also the 'seeds' of the future developments that can be learned through the expansion of a health care activity in practice.

3 Chronic illness and health care organization in Finland: Towards a zone of proximal development

3.1 Introduction

In this chapter, I investigate the increased incidence and prevalence of chronic illness after the Second World War and the development of health care organization in Finland. Changes in the incidence and prevalence of diseases are connected to the history of instrument creation in the care of illnesses (Vuorinen, 2002, p. 221). Furthermore, observations of health care practice show that the advancement of medical knowledge, medical specialization, and technological innovation appears in parallel to each other (Wiener & al., 1984, p. 15).

From the perspective of this study, it is important to study *why* the present health care organization for multiple and chronic illnesses emerges as complex and aggravated by boundaries. Therefore, I will trace the historical sources of the object of health care, e.g., the chronic illness and the prevalent health care organization. Tracing the historical sources of the object of health care enables determining the location of the current boundaries in the organization of health care for multiple and chronic illnesses and shows how the boundaries have evolved during the history of health care organization. Interpreting past developments is also important because it enables the outline of a zone of proximal development. The zone of proximal development describes an area of change and the development of present actions in terms of the past and future. Possible futures are collectively envisioned solutions to problems, disruptions and gaps in the present activity (Engeström, 1987, p. 174).

In activity-theoretical studies, the object-historical analysis of activity explores the developmental phases of an activity, including its object (Engeström, 1987). However, the aim is not only to outline the periods in the object-history but to uncover the contradictions giving rise to transitions from one developmental pe-

riod to another (Engeström, 1987, p. 325). The definition of phases is based on transitions that are triggered by internal contradictions of an activity system as well as qualitative transformations of the object of an activity. Hence, the object is not “self-contained” but also undergoes transitions as a system of object-activity, as Engeström himself maintains:

Thus, the analysis takes as its point of departure the qualitative transformations of the object, itself understood as an activity system. However, the system of object-activity cannot be regarded as external to the central activity, to be only ‘connected’ with it. To the contrary, the object is to be analyzed above all as an integral component of the central activity while simultaneously acknowledging it as a relatively independent activity system of its own. This procedure, moving ‘from within’ the central activity out to the object-activity and back into the central activity, is essential if the researcher is to preserve his grasp of the self-movement, the self-organizational dynamics of the activity under investigation. (Engeström 1987, p. 325)

In this study, the emergent object-activity is the chronic illness embedded in the patient’s life while the central activity is the health care organization. Engeström (1995b, p. 135) points to three methodological questions that need to be settled in conducting the historical analysis. First, which features of an activity are focused on in the analysis? Second, how is the development of an activity divided into periods? Third, how are the transitions from one period to another explained?

First, the present study investigates a multi-organizational context of health care organization (see figure 1.2 in chapter 1.3). The diverse providers in distinctive organizations such as professional, administrative, social service, economic, educational, and political activity systems contribute to the organization for chronic illnesses. However, the central activity, i.e., the health care organization, and its object-activity are only explored in this study. The features that are examined are the organizations of health care provision, including its subjects, objects, tools, rules, and the division of labor. Furthermore, the creation of new diagnostic and curative means are explored in order to define the “self-organizational dynamics of the activity under investigation” (Engeström, 1987, p. 325). In particular, the health care organization for the chronic illnesses that were selected for the development project (see chapter 1.2) are studied, i.e., pulmonary, heart and renal diseases as well as rheumatoid arthritis and diabetes.

Second, the periods of the development of the health care organization are divided according to major changes in the object, the chronic illness. The periods¹³ are (1) the emergence of health care organization and chronic illnesses

¹³ The time periods are flexible, heuristic devices, not strictly bounded categories.

between 1663 and 1944, (2) health care organization and the increased prevalence of chronic illnesses between 1945 and 1971, (3) health, illness and disease as the object of the expanded health care organization of chronic illnesses between 1972 and 1992, and (4) the increasing complexity of chronic illnesses and the diversity of multiple providers from 1993 onwards. Important laws and regulations are indicated to mark the change in health care provision and the boundaries of health care organizations. In object-creation activity, the developmental periods are divided according to medical inventions and the treatment of illnesses. Every renewal of health care organization is, therefore, a re-construction of the objects as well as the organizational boundaries.

Third, activity systems appear as tension-laden, unstable, and multi-voiced entities involving various traditions and interests (Engeström, 1987; R. Engeström, 1999a; Engeström, 2001). These underlying tensions reflect the internal contradictions of activity while also acting as mobilizing forces of change in the activity. In this study, transitions from one period to another are conceptualized as solutions for challenges that require new forms of organizing in health care. The transitions reflect the internal tensions of the time, leading to the reconstruction of the object and the health care organization.

The main references in this chapter comprise general histories of Finnish health care (Pesonen, 1980; von Bonsdorff, 1975; Vuorinen, 2002). These sources are complemented by documents obtained from primary and secondary care, introductory interviews with representatives from both organizations (altogether 13 interviews), general histories of Finnish health care in the form of reports from the Ministry of Social Affairs and Health and the National Research and Development Centre for Welfare and Health, professional journals of the Finnish Medical Association, and journals of Finnish patient associations.

First, I present the basis of Finnish health care organization before the Second World War and the care of chronic illnesses. After that, I describe the developments of the health care organization after the Second World War when the prevalence of chronic illnesses was increasing. Then I explore how health care provision expanded during the 1970s and 1980s, while chronic illnesses also expanded as objects of care provision. Finally, I examine the developments in the 1990s and 2000s that are marked by the increasing complexity of chronic illnesses and the diversity of multiple providers. Table 3.1 provides an overview of the rise of multiple and chronic illnesses, the development of the health care organization and the key boundaries related to the periods that are explained in more detail in this chapter.¹⁴

¹⁴ A reader can catch the main points of the history of Finnish health care organization in table 3.1 and skip straight to section 3.5, which describes the present challenges of the Finnish health care organization.

Table 3.1. An overview of the rise of multiple and chronic illnesses, the health care organization, and the key boundaries related to the periods

Periods of development	Rise of multiple and chronic illnesses	Health care organization	Key boundaries
1. Finnish health care organization from 1663 to 1944	Chronic illnesses treated in the shadow of epidemics	Provincial physicians, municipal physicians, hospitals	Professional autonomy in treating illness vs. lay knowledge, emergence of the boundaries between general practice and hospital care
2. Finnish health care organization from 1945 to 1971	Increased prevalence of chronic illnesses	Municipal physician system, creation of hospital network	General practice and hospital care, emergence of the specialty boundaries in internal medicine and pulmonary diseases as well as in sub-specialties of cardiology, nephrology, endocrinology, and rheumatology
3. Finnish health care organization from 1972 to 1992	Treatment of chronic illnesses expands into treating health	Health care centers, primary, secondary and tertiary hospital care	Boundaries between levels of care, stabilization of specialty and sub-specialty boundaries
4. Finnish health care organization from 1993 to the present day	Intertwining of organisms, representations, and technologies	Management by results, personal doctor system in primary care, integrated care pathways, current care guidelines	Consolidation of the boundaries between levels of care and between specialties and sub-specialties as an implication of cost-effective care and management by results

3.2 In the shadow of epidemic diseases — the care of chronic illnesses before 1945

The basis of the present health care system was created in the 18th century in Finland. During this period, chronic illnesses had a minor position as an object of care (Pesonen, 1980). However, it is important to review the development of the health care system from its beginnings in order to understand the challenges that emerged when the dominant position of epidemics such as tuberculosis receded and the prevalence of chronic illnesses increased. The boundary respecting the autonomy of medical professionals in the curing of illnesses is derived from the Swedish era in the 17th century. The development of the health care system can be divided into three periods: (1) Swedish sovereignty, (2) the time of autonomy under Russian sovereignty, and (3) the time of national independence from 1917 to 1945. Next, I will give a short description of the three periods.

3.2.1 The emergence of health care organization during Swedish sovereignty from 1663 to 1808

During the period of Swedish sovereignty, the foundations of the profession of medicine and the health care organization were laid in Finland. At that time, the level of hygiene and living conditions were poor in Finland. Besides epidemic diseases such as plague and cholera, high child mortality kept the population low (Vuorinen, 2002).

The development of the Swedish and Finnish health care system progressed in the 17th century when a professional medical community, *Collegium Medicorum*, was founded in 1663. The establishment of scientific medicine and education at the Turku Academy had already started in 1640. However, permission to practice medicine as a profession was received from the medical collegium at Stockholm (Pesonen, 1980).

Health care organization in the 18th century included provincial medical officers and general hospitals. The first medical officer began his employment in 1749. At the end of the 18th century, there were eleven medical officers in Finland (Pesonen, 1980, p. 257). The establishment of hospitals was slow. The first hospital in the modern sense was founded in Turku in 1756. At the end of the 1700s, six provincial (or district) hospitals existed. The first hospitals were small, having only 2–12 beds and depended on the efforts and economic support of local communities (Stranberg, Valtonen & Voutilainen, 1978). But the general public kept away from hospitals; in the 17th century the function of hospitals was to isolate seriously and chronically ill patients and other hopeless cases from society (Pesonen, 1980, p. 420).

3.2.2 The emergence of the health care system during the time of autonomy in the years 1809–1916

During the time of autonomy, the profession of medicine secured its position and the health care organization became more established. At that time, epidemic diseases such as smallpox, dysentery, syphilis, and cholera ruled the country. Tuberculosis also had one of its first peaks as a fatal disease during the 1850s. Chronic illnesses were not at the center of interest because epidemic diseases required attention in the health care system. However, academic medicine did investigate chronic illnesses such as bronchitis, asthma, rheumatic fever, and arteriosclerosis (von Bonsdorff, 1975). Chronic diseases were also provided care in general practice. As early as 1839, the provincial medical officer Ringbom reported on cardiac health problems, which he thought were connected to unhealthy food and heavy work (Pesonen, 1980, p. 261). Many medical inventions of the time improved the diagnostics of chronic illnesses. Due to the ineffectiveness of treatment, these inventions were not taken into general use. For instance, the EKG has already been invented in the 1800s, but was not adopted into general use until the 1940s in Finland (Siltanen, 1990, p. 113).

During the time of Russian sovereignty, a central administration for health care organization was established. The collegial organization called *Imperial Collegium Medicum*, founded in 1811, maintained responsibility over health care in Finland. Later in 1830 it became the central office for the administration of medical services in Finland, and in 1878 its name was changed to The National Board of Health (von Bonsdorff, 1975, p. 15). During the time of autonomy, health care was mainly provided by the state.

The health care system included provincial medical officers whose responsibilities were legally outlined in 1832. The number of medical officers increased to fifty in the 1850s. The medical officers were responsible for both public health and the treatment of illnesses. However, reports by inspection officials show that medical officers used most of their time to cure common illnesses. In spite of their continuous contact with the population, medical officers were not always popular among the inhabitants. Neither did people always trust their medical care but went to “the wise men or women” for help with common diseases (Pesonen, 1980, pp. 257–264). The institution of provincial medical officers was complemented with the addition of municipal physicians in 1882. Municipalities began to receive financial aid for the hiring of physicians. The number of physicians increased quickly from 18 municipal physicians in 1890 to 92 physicians at the end of 1901 (Pesonen, 1980, p. 405).

The enactment of the first hospital law in 1814 furthered the development of general hospitals. The hospital organization was divided into general and venereal

hospitals. The first general hospitals were founded in distant parts of the country from 1841 onwards. In 1894, there were twelve general hospitals in the country (Pesonen, 1980, pp. 423–428). Besides state hospitals, there were also city hospitals and private hospitals. In 1881 the municipalities began to run hospitals, and in 1901 there were 225 hospital beds in municipalities and 320 hospital beds in urban areas (Pesonen, 1980, p. 432). Until 1878, the hospitals did not receive patients who had incurable diseases or lung diseases (Pesonen, 1980, p. 106). In 1878, the focus of care expanded from the cure of diseases to the re-establishment of an ill person's health (Pesonen, 1980, p. 456).

3.2.3 The period of national independence from 1917 to 1945

During the first years of independence, the profession of medicine and the health care organization stabilized. At that time, most common diseases were infectious diseases such as scarlet fever, measles, typhoid fever, whooping cough, and tuberculosis. In particular, the treatment of tuberculosis required plenty of resources in the health care system (Härö, 1992). Venereal diseases were also common, as well as minor diseases and accidents caused by poor hygiene and the excessive use of alcohol (Kauttu, Reinilä & Voutilainen, 1983, pp. 133–138). During this period, internal diseases became more prevalent, but they could not always be effectively cured.

A health care act in 1928 directed that the National Board of Health was to be responsible for public health in the country. Medical doctors and registered nurses provided the care in practice. The health care act was completed in 1939 (Public Health Care Act 197/1939) when a law of public health care was enacted. The law aimed at improving the medical provision throughout the country by increasing the number of municipal physicians and public health nurses. However, the law was not implemented until 1943 (Pesonen, 1980, pp. 414–418). Municipal physicians most often treated acute diseases such as pneumonia, appendicitis, intestinal obstructions, or gastric ulcers. They also provided care for chronic illnesses such as bronchial or stomach catarrh, rheumatoid arthritis, and heart troubles (Kauttu & al., 1983, pp. 133–138). The hospitals were developed in parallel with the municipally organized medical system (Pesonen, 1980). In 1920, there were 256 general hospitals with 6915 hospital beds, 16 tuberculosis hospitals with 755 beds, and 28 mental hospitals with 2743 hospital beds. The state owned most of the general hospitals until the 1910s when municipalities became the main owners. In 1930, new legislation guaranteed the state's support for the running of tuberculosis and mental hospitals. The renewal doubled the number of hospitals and hospital beds at that time (Sinkkonen & Nikkilä, 1988).

The specialties of internal medicine and lung diseases began to gain ground in the 1930s (Pesonen, 1980, p. 456). The medical profession obtained the right to oversee its specialties, and many professional communities were established (Pesonen, 1980, pp. 669–670). In 1932, there were 11 specialties, including internal medicine and pulmonary disease (Pylkkänen, 2002). Chronic illness became prevalent, and the development of diagnostics and care emerged for internal diseases. For instance, cardiovascular diseases were treated with digitalis and other medications common at that time (von Bonsdorff, 1975, pp. 132–133). In the 1930s, 34 000 people were estimated to suffer from rheumatism in the population (Laine, 1985, pp. 17–18), but the care provision for arthritis held a minor position when compared to the treatment of other diseases (Heikkinen, 1987, p. 7). The care provision for chronic illnesses included the care of diabetes when insulin was discovered in the 1920s (Tirkkonen, 1998). The care provision was not, however, successful at first since patients died quite soon after the treatment.

An example of this care provision is a case documented by Saraheimo (1990). A patient went to see a physician in the spring of 1922 because of exhaustion, thirst and increased urination. A diagnosis of abdominal tuberculosis was made. Then the patient caught a cold and did not see his physician until the autumn of 1922. The diagnosis was the same as was made at the previous visit. The patient was provided with powders and bottled medicine, but they did not help. However, the patient continued to be ill and he sought help from the hospital in April of 1923. When he arrived at the hospital, he was in poor condition with a high amount of sugar in his urine. At first he was given a diet that included small amounts of carbohydrates and protein, but plenty of fat. He was also given soda and spirits. For some days he ate only vegetables. In August of 1923 he was in poorer condition, and it was decided to administer insulin treatment. In two days he was already feeling better, and urine tests showed only small amount of sugar. The insulin treatment was continued for one week, and after ten days of treatment the insulin was discontinued. The patient left the hospital in October of 1923 with a dietary prescription. The diet included little carbohydrates and protein, but plenty of fat. The period after the hospital care is not known, but it is documented that the patient died in July of 1924.

The case of the diabetes patient is an example of the need for improved treatments that patients with internal medical problems began to create for the health care organization. Such needs may be regarded as expressions of contradictions between the tool-object development and the rules, communities, and division of labor in health care organization. This development marks the beginning of the first period in the object-history of chronic illnesses and health care organization. During this phase, chronic illnesses began to overtake epidemics as a focus of health care organization, which had to develop to meet these challenges.

3.3 Health care organization and the increased prevalence of chronic illnesses

The change in the pattern of diseases marks the phase of the increased prevalence of chronic illnesses in Finland. During this transition, the needs of care provision for chronic illnesses increased, while care for epidemics such as tuberculosis decreased. The invention of penicillin and its use in the care of tuberculosis and other epidemics revolutionized the western pattern of illnesses in the 1940s. Statistics show that tuberculosis was the cause of death in 7844 cases in 1940, whereas it was a terminal disease in only 3750 cases in 1950, and by the 1960s the number of deaths was 1158 cases (Härö, 1976). The discovery of new medications such as cortisone (Laine, 1985, p. 59) and the improved use of insulin advanced the provision for chronic diseases (Tirkkonen, 1998). Furthermore, new technical inventions and techniques, and the generalized usage of earlier inventions improved diagnostics in medicine. For instance, new techniques such as cardiac catheterization or the common use of earlier inventions such as the EKG promoted the diagnosis of heart diseases (Teerijoki, 1990).

In Finland, this phase marked a period of rebuilding after the Second World War. The health care system expanded into all areas of the country as part of this rebuilding. The municipal officers of health, often general practitioners, were in charge of public health, while the network of general hospitals secured the care of diseases in hospitals. The development of medicine also affected the differentiation of medical specialties and created new boundaries inside hospital care. Next, I will describe this development in more detail. The chapter represents also the emergence and specification of the object, e.g., chronic illnesses, during the creation of new diagnostic tools, medicine, and treatments.

3.3.1 Health care organization during the increased prevalence of chronic illnesses

Municipally provided health care was renewed by the Public Health Care Act (Act 197/1939) in 1939 and implemented in 1943. The law aimed at better availability of public health services throughout the country. It increased the number of municipal physicians as well as their responsibilities as public health officers (Pesonen, 1980, pp. 417–418). Besides treating common illnesses, municipal physicians were responsible for the provision of child welfare and maternity clinics, schools, homes for the elderly, environmental hygiene, and the general instruction of public and municipal administration (Kauttu & al., 1983, pp. 93–94). The

multiplicity of tasks was problematic, and many municipal physicians were overworked¹⁵ (Kauttu & al., 1983, pp.14–15).

During this period, municipal physicians had better medications and diagnostic tools in use than before, which enabled better diagnoses and care of illnesses. Municipal physicians treated most of their patients themselves, and even though most patients had serious, often chronic diseases, only 15% of patients were referred to hospitals during the 1960s (Kauttu & al., 1983, pp. 99–100). Approximately every third patient had a chronic illness, and some patients had many diseases. The number of visits by patients with many illnesses was double that of patients with a single diagnosis (Kauttu & al., 1983, p. 104). Towards the end of the 1960s, the work of municipal physicians changed, and they began to treat more general ailments such as respiratory track infections, back pain, and accidents because the more severe illnesses and chronic illnesses were treated at hospitals (Kauttu, 1983).

Statistics illustrate the vast increase in hospital beds during this period in Finland. For instance, during the 19th century, there was one hospital bed for every 15 000 inhabitants, in 1946 the figures were 1:130, and in 1976 1:100 (Stranberg, Valtonen & Voutilainen, 1978). During this phase, the renewal of the hospital organization was carried out in a series of hospital laws and building projects. Creating the hospital network was problematic since the hospital laws needed to be readjusted at the time of their implementation (Pesonen, 1980). The Law of Central Hospitals, which was enacted in 1943 (Act 413/1943), provided specialized hospital care throughout the country. The country was divided into 20 central hospital districts (with the addition of one district in 1951), but the law was not implemented until 1960 (The Hospital Law 49/1956)(Pesonen 1980, 609–610). The law on university hospitals in 1956 changed some central hospitals into university hospitals (Pesonen 1980: 610). The law on municipal general hospitals in 1965 gave some direction for the running of general hospitals. All hospitals were granted financial support from the state. Central councils ran central hospitals, while a consortium of municipalities or individual municipalities were given the sole responsibility for regional hospitals and local hospitals (Pesonen, 1980, pp. 598–610). This type of ownership enabled hospitals to function independently of each other (Hongisto, 1969).

¹⁵ For instance, statistics show that at the beginning of the 1960s a community physician worked approximately 58 hours per week, and received approximately 117 patients per week and 6000 patients per year (Kauttu & al., 1983, pp. 93–94).

Implementation of the new hospital laws coincided with the hospital building “project.” The prolongation of the project had the effect that the beds assigned to each hospital did not match the altered needs of the hospitals. For instance, otology wards were not considered necessary in all central hospitals when the charters of foundation were signed, but these specialties were needed by the time of implementation (Pesonen, 1980, pp. 606–607). Central hospitals usually housed eight specialties: internal medicine; surgery; maternity and gynecologic wards; pediatrics; otology, rhinology, and laryngology; ophthalmology; neurology; and dermatology. Since the frequency of epidemics was in decline, only a few beds were needed for them instead of a whole hospital ward, and those beds could be given to internal medicine patients (Pesonen, 1980, p. 684).

3.3.2 Specialties and the increased prevalence of chronic illnesses

New medications, the X-ray testing of the whole population, well-organized care in the network of tuberculosis sanitariums and offices, and improved sanitary conditions reduced the prevalence of tuberculosis in Finland (Härö, 1998). The reduction of tuberculosis in the population impacted the amount of beds designated for the care of tuberculosis. In 1970 there were 3806 beds in tuberculosis sanitariums, while 6001 beds were provided in 1950 for the provision for tuberculosis (Tammi-vaara & Venho, 1978). The extra beds were mainly provided for internal medicine patients, in particular for patients suffering from rheumatic diseases. Municipal physicians and general hospitals treated other pulmonary diseases such as chronic bronchitis, asthma, lung cancer, and occupational lung diseases. In the treatment of asthma, antihistamines became popular in the 1940s, and cortisone was adopted into use in the 1950s. Since then, asthma has been a commonly known illness among pulmonary diseases (Helsinki Medical Journal, 1993).

After the fight against epidemics became less of a priority, cardiovascular diseases took up the position of a ‘major national burden’ in Finland. However, as Kannisto had already noticed in 1947, coronary diseases were more prevalent in eastern than in western Finland (Pesonen, 1980). During this period, diagnostics, medication, and care practices for heart diseases improved in Finland. The EKG was adopted for the diagnostics of coronary artery disease in the 1950s, cardiologists began to use ultrasonic examination to diagnose heart failure in the 1960s, and angiography was tested as early as the 1960s (Siltanen, 1990). A new era began for the treatment of heart insufficiency when diuretic medication was discovered in the 1950s. Along with the discovery of beta blocking agents, diuretics advanced the control of hypertension (Siltanen, 1990). Care practices also changed during this period. Heart specialists were able to save many patients with improved medication and tools in the 1960s. Long-term rest was recommended for infarct

patients in the 1950s, but in the 1960s they were encouraged to undergo rehabilitation (Sjögren, 1991). Compulsory tuberculosis testing with chest x-rays enabled the examination of heart diseases in a large population in 1962. Later, EKG examination was conducted jointly with x-rays (Teerijoki, 1990, pp. 56–57). The Finnish Heart Association was active in many studies. For instance, the study of policemen in 1966 conducted by Kalevi Pyörälä, Pentti Siltanen, and Sven Punsar increased knowledge about the risk factors of coronary artery disease among Finnish men (Teerijoki, 1990, pp. 57–59). The seven countries study (Keyes, 1970) reported the effects of certain risk factors such as high cholesterol, high blood pressure, and cigarette smoking in heart diseases.

Private providers delivered care for arthritis and other rheumatic diseases. Some key professionals, influential individuals, and the Rheumatism Association and Foundation enabled the care provision for rheumatic diseases (Laine, 1957). The rheumatism committee set up by the state estimated that 110 000 individuals suffered from rheumatic diseases in 1945 in Finland (Heikkinen, 1987, p. 7). The committee emphasized the lack of care provision and the necessity of rehabilitation for rheumatic diseases. Municipal physicians mainly treated patients suffering from rheumatic diseases (Kauttu & al., 1983). Hospital care for rheumatism was established in 1946 at Kivelä hospital in Helsinki, the Rheumatism hospital at Heinola, and at rheumatism offices organized by the Rheumatic Association and Foundation (Laine, 1985). Medication, diagnostics, and care practices have improved considerably since 1945 when ACE preventives and cortisone were invented in 1949 (Laine, 1957). The diagnostics of rheumatoid arthritis improved when a method of detection of the rheumatic factor was discovered. Orthopedic treatments also developed enormously as a choice of conservative care (Laine, 1985). Patients were given information about their illness and its treatment, and medical professionals outlined an overall understanding of the patient and his or her life situation (Laine, 1962). Patients appreciated the care in the specialized institutes, but they complained about insufficient care resources, the lack of specialized knowledge, and insufficient opportunities for x-ray examinations and rehabilitation (Tuominen, 1967). The position of patients suffering from rheumatic diseases improved in 1954 when they began to receive the benefits listed in the Invalid Act (Heikkinen, 1987, p. 37). The National Pension Institute, the state, municipalities, and some communities supported the hospital care of individual patients at the Heinola hospital (Ponteva, 1953). Patients over fifty years of age were not accepted, and neither were all rheumatic diseases given care provision. For instance degenerative arthritis was not treated (Ponteva, 1953).

While medical discoveries in cardiologic and rheumatic diseases benefited large numbers of patients, renal patients were a small group that enjoyed the advancements of medicine. During the 1940s, the provision of care for renal disease

was limited. Sulfa-amid medicine was discovered to be useful for the treatment of urinary tract infection. Blood pressure problems could also be treated, but terminal uremia was fatal, and patients died soon after. A series of discoveries resulted, however, in improvements in the diagnosis and treatment of renal patients in the 1950s and 1960s. For instance, renal transplants could be provided as treatment for chronic renal disease in the 1960s (Kuhlbäck, 2002). During the first years of provision, only a few clinics were able to provide these treatments. Therefore, the patient association for renal and transplant patients, founded in 1967, began to pursue better opportunities for care provision in public health care (Heinonen & Saloranta, 1995). The methods of curing renal diseases were still generally unknown among medical professionals, and the criteria for treatment was strict. The number of renal patients receiving dialysis or renal transplants increased slowly during the 1960s. In 1972, a total of 100 dialysis and renal transplant patients were provided care in Finland (Stenman, 1995).

Diabetics were another group of patients alongside rheumatic and renal patients whose care provision depended on single practitioners, private efforts, and the work of patient associations (Tirkkonen, 1998). Insulin was available for the care of diabetes in the 1940s, but patients had to pay for medication as well as the care equipment themselves. For this reason many diabetics stopped using insulin. Patients and even professionals also lacked information about the nature of the disease. Professionals had no general recommendations for a diet; every professional had to give his own dietary advice. Patients and their intimates often believed that diabetes is caused by an infection, which prompted them to keep the disease secret because they did not want to be quarantined. The Finnish Diabetes Association and, in particular, the Helsinki Diabetes Association, improved the position of and provision for diabetics through general instruction and patient training as well as economic support. During the 1950s, better testing equipment was invented for the self-care of diabetes. But it was not until the 1960s that better quality insulin and dietary prescriptions were adopted for diabetes care (Tirkkonen, 1998, p. 94). A health insurance act in 1964 improved the position of diabetics when insulin and the equipment needed in the care of diabetes began to be provided by public funds (Tirkkonen, 1998, p. 76).

3.3.3 Challenges of health care organization for multiple and chronic illnesses at the end of the 1960s

The development of diagnostics and medication increased the trust of the general public in medicine's ability to solve problems in the 1960s. People sought out municipal physicians for medical aid for common colds, flus, and aches, which increased the demand for health services. The increased prevalence of chronic

illnesses also raised the need for care. Municipal physicians and hospitals were able to provide better care, but the queues for services were long, and the services were not available in all parts of the country (Engeström & al., 1988). Some services were only available in privately provided care. Therefore, the need arose for a more extensive system that would serve everyone in all parts of the country. These demands lead to the creation of health centers and a more extensive hospital network in the 1970s. This development also divided the care organization into minor ailments treated at the municipal care delivery and more severe problems treated at the hospitals (Engeström & al., 1988).

The discussion of chronic illness in terms of its nature and care created the need for the expansion of the health care organization at the beginning of the 1970s. It was recommended that the defects acquired during a person's lifetime, such as ailments characteristic of aging, should also be considered chronic illnesses (Grönmark, 1970). Grönmark estimated that the extension of health care for chronic illnesses raised the need for 10 300 extra hospital beds. Sievers (1970) maintained that the problems of chronic patients ought to be approached as an epidemiological question that includes those patients without a proper diagnosis. According to this estimation, 214 117 individuals were without medical care in 1970, and many of those would have benefited from preventive care for more severe diseases (Sievers, 1970). Ojala (1970) called for more effective health care that would include guidance, health promotion, and testing. The development of diagnostics in early phases of diseases, effective acute care, and home care could also impact the effectiveness of health care.

The hospital network was organized into central, regional, and local hospitals at the end of the 1960s. Problems were observed in the coordination between hospital levels and between hospitals and municipal physicians. Cooperation within the hospital organization was considered difficult because of the independence of the hospital management (Hongisto, 1969). Municipal and hospital physicians experienced problems with the communication between hospitals and municipal health offices when patients were discharged from hospitals to primary care (Seppälä, 1971). Patients also did not have enough information about their illnesses and their care when they left the hospitals. The inability of the medical specialties to transfer patients from one ward to another without a municipal physician's referral mirrors the problems in communication between the specialties (Seppälä, 1971, p. 986). The problems in cooperation also appeared in the care of patients provided at various locations over a patient's lifetime. Patients had to explain their history of illnesses and diseases, since patient documents were scattered over various locations of care (Benson, 1969). This caused uncertainty in the care practice. According to Ruikka (1968), geriatric patients who suffered from multiple diseases required more specialized care than was available at regional hospitals.

In sum, the main challenges of the health care organization in the 1960s related to the expanding object of care and the problems associated with structural integration and cooperation between different providers. The expansion of chronic illness to include prevention in health care provision increased the prevalence of chronic illnesses in Finland. This expansion marks the transition from the increased prevalence of chronic illnesses into the extended health care organization of chronic illnesses.

3.4 Health, illness, and disease as objects of the expanded health care organization of chronic illnesses

The boundary between treating illness and treating 'health' became blurred when the provision of 'health' was accepted as a target of health politics in parallel with treating illnesses. On the ideological level it was considered that the treatment of 'health' prevented illnesses and reduced the need to treat them (Autio, 1975). The expansion of the object into health, illness, and disease increased the volume of outpatient care. The change from emphasizing hospital care into favoring outpatient care was outlined in the Primary Health Care Act, 1972 (Act 66/1972). It directed municipalities to take responsibility for health-improving procedures (Pesonen, 1980). In the following subsection, I characterize health care organization and chronic illnesses as objects of care at the beginning of the 1970s.

3.4.1 Health care organizations and the expanded care provision of chronic illnesses

The implementation of the Primary Health Care Act in 1972 secured health care services for the entire population of Finland. The Primary Health Care Act integrated the fragmented legislation of primary health care. For instance, Engeström & al. (1988, p. 69) listed seventeen laws that directed the work of municipal physicians at the end of the 1960s. The preparation of the Primary Health Care Act was a longitudinal process involving committee work and parliament discussions before its enactment in 1972 (Pesonen, 1980, pp. 688–691). Besides integrating services, the Primary Health Care Act also provided the basis for new administration, planning, and financing of the health care organization. Among the administrative reforms were the foundation of primary care units (health care centers), regulations for the municipal governance of health services, and a system of planning that provided tools for administration (Sinkkonen & Nikkilä, 1988, pp. 44–45). The system of planning included five-year plans for health care provision on the municipal, county, and state levels (Pesonen, 1980, p. 693).

Some research programs and experiments provided practical information on the expanded object of public health outlined in the Primary Health Care Act. The North Karelia project in the years 1972–1977 is a well-known example of a large-scale effort to combat chronic diseases in primary health care (Puska, Tuomilehto, Nissinen & Vartiainen, 1995). The knowledge reported in some influential studies (Keyes 1970) about causal risk factors in the progress of cardiovascular disease (CVD) acted as a springboard for launching a community-based project in North Karelia with local representatives and World Health Organization experts (Puska & al., 1995). The project examined the connections between community lifestyles and the risk factors of CVD, e.g., cigarette smoking, elevated blood pressure, and high serum cholesterol (Puska, Tuomilehto, Salonen, Nissinen, & al., 1981). The intervention methods included hypertension control, dietary consultation, and information about CVD risk factors. The project was carried out in health care centers with public health nurses and health center physicians participating in the project. The project reported on favorable changes in the risk factors of chronic diseases and in the health of the population (Puska & al., 1981). The evidence of the possibility of preventing chronic diseases was adopted nationwide as an object of health care provision. For instance, Kauttu (1992) reports 15 000 persons were put on hypertension medication within a few years after the North Karelian Project published its results.

A practical implication of the Primary Health Care Act was a nationwide project to build health care centers. Health care centers integrated diverse practices such as shared consultation spaces for physicians, maternity and child welfare clinics, and dentist, laboratory, and x-ray services (Pesonen, 1980, p. 693). The work of health center physicians included patient visits, prevention and health care at maternity and child-welfare clinics, work at health center hospitals, administrative tasks, the preparation of health certificates, and the provision of acute care (Parvinen, 1975).¹⁶

During this phase, the hospital building project was completed when the last central hospital was opened in 1979. General hospitals housed altogether 33 579 beds at the end of 1976. Hospital legislation was renewed in the hospital laws of 1978 and 1987. The new directions stated that central hospitals were to oversee the central hospital districts, while local hospitals were integrated into health care

¹⁶ In 1974, an average physician consulted approximately 521 patients in one month. According to Parvinen (1975), an average week of a health center physician included approximately 16–20 hours of patient consultations, 4–5 hours of prevention and health care work at the maternity and child welfare clinics, 2 hours at a local hospital, 2.4 hours of administration, and 2.7 hours in the preparation of health certificates. Furthermore, health care physicians worked at acute care for approximately 10 hours per week.

centers. The panorama of illnesses changed in hospitals during the 1970s when the number of elderly patients increased (Kauttu, 1992). The patients suffered from tumors, degenerative heart disease, or thighbone fractures. The average length of stay at a hospital remained the same as before, approximately 15 days, but the frequency of visits increased, indicating an increase in the prevalence of chronic illnesses. Health programs combating hypertension or diabetes aimed at preventing illnesses, with the consequence of increasing the number of patients with chronic illnesses (Pesonen, 1980).

The number of physicians also increased after the Primary Health Care Act. In 1960, altogether 2827 physicians provided health care in Finland, while in 1980 the number of health center physicians was 2272 and 3864 physicians worked at hospitals. The Primary Health Care Act had an impact on the number of other professionals in the health care organization. For instance, the number of nurses tripled during the period from 1960 to 1985. In addition, health care centers and hospitals hired various new professionals such as speech and occupational therapists, laboratory and x-ray nurses, and dental nurses (Sinkkonen & Nikkilä, 1988, pp. 60–66). Professional training was reorganized at the beginning of the 1970s. The law on the practice of medicine was also revised in 1978. The emphasis on outpatient care brought along with it a new specialty in primary care, namely the specialty of general practice (Keinänen-Kiukaanniemi, 1993).

3.4.2 Specialties and the expanded health care organization of chronic illnesses

The care object of pulmonary disease changed when tuberculosis receded and the prevalence of asthma and obstructive pulmonary diseases such as COPD (chronic obstructive bronchial disease) increased.¹⁷ Multiple medications for the treatment of asthma and new technical opportunities for providing care for COPD improved the care of pulmonary diseases (Poppius, 1983). Yet the variety of medication and the advanced means of provision brought new challenges. For instance, the etiology of asthma required individually based regimens, good patient compliance and self-care, and continuity in care provision (Lahdensuo, 1983). Asthma patients seemed, however, to fall between primary and hospital care as only acute periods were given provision instead of delivering long-term care (Lahdensuo, 1983). The re-structuring of pulmonary care seemed altogether problematic when extra beds in tuberculosis sanitariums were mainly designated for internal medicine patients

¹⁷ Elo (1974) estimates that the frequency of asthma showed a 1–2% prevalence in age distribution at the beginning of the 1970s, whereas 6–8% of men and 1% of women over fifty years of age suffer from unspecified pulmonary diseases such as chronic bronchitis or emphysema which handicap their normal life.

(Tammivaara & Venho, 1978). In 1976, general hospitals provided care for 40 562 pulmonary patients (633 396 hospital days), although patients could have benefited from the treatments and diagnostic opportunities available at tuberculosis sanitariums from lung specialists.

The prevalence and incidence of heart diseases decreased in Finland in the 1970s and 1980s in parallel with the improvement of provision for heart diseases. For instance, successful prevention and improvements in acute coronary care had an impact on the decline of heart diseases in Finland (Salomaa, Miettinen, Kuulasmaa, Nieminen & al., 1996). New methods of heart surgery, medication, and diagnostics expanded the object of providing care for heart diseases. Bypass operations for the heart were adopted into use in heart surgery, and 2171 bypass operations were performed in 1988. Angioplasty became generally used and was applied in 297 cases in 1988 (Siltanen, 1990, p. 112). The first heart transplant in Finland was performed in 1985 (Partanen, Heikkilä, Hellstedt & Nieminen, 1997). The increased use of acetyl salicylic acid (aspirin), beta-blockers, and ACE inhibitors improved the treatment of coronary artery disease (Salomaa & al., 1996). The diagnostics of heart diseases progressed in the 1980s when 'second generation' tools based on computer technology were implemented (Siltanen, 1990, p. 113). The North Karelian project (Puska & al., 1995) developed a new framework for the community-based control of cardiovascular diseases as described in the previous chapter. From 1983 to 1992, the FINMONICA study examined the incidence, recurrence, and case fatality rates of coronary events in coronary heart disease mortality rates in Finland (Salomaa & al., 1996).

During this period, privately organized care for rheumatic diseases was established in public health care. Health care centers were expected to identify new cases of illness and provide outpatient care for those whose diagnoses were confirmed, and the medication for these patients was chosen at specialized hospitals (Oka, 1978). Arthritis patients were, however, mainly provided care in the 1970s at the Heinola hospital for rheumatic diseases and at rheum offices owned by the Rheumatic Foundation and Association (Heikkinen, 1987, p. 22). The care provision for rheumatic diseases also improved when wards at tuberculosis sanitariums were designated for rheumatic patients. The object of treating rheumatic diseases was clarified during this period when the regimen, which included diagnostic criteria and care practices for arthritis, was implemented in 1979 (Nivelreuma,¹⁸ 1985). In particular, the regimen emphasized early intervention for infected joints in the treatment of arthritis. The recommendation was that patients should be provided for as psychosocial wholes, and encouraged to practice self-care and to

¹⁸ *Rheumatoid Arthritis. Examination and Clinical Care Guidelines* (1985). The Finnish National Fund for Research and Development.

stay informed about their illness. The choice of medication was individually based and tested at special hospital wards or outpatient clinics.

During the 1970s, the care of renal diseases expanded in public health care. For instance, dialysis could be provided throughout the country in 1975 (Stenman & Grönhagen-Riska, 1995). While just 34 dialyses were performed in 1961, 6094 dialyses were performed in 1969 and 26 620 dialyses in 1979 (Kuhlbäck, 2002). From 1973, dialysis could also be provided for chronic patients, but patients over 55 years of age could not be provided until the 1980s (Stenman & Grönhagen-Riska, 1995). Renal diseases were mainly treated in specialized wards and outpatient clinics at central or university hospitals. Besides hemodialysis, also CAPD (continuous ambulatory peritoneal dialysis) was used from 1979 onwards. The frequency of renal transplants increased when more effective inhibitors (cyclosporin) and new legislation for transplants were adopted in the 1970s. According to statistics, 10 renal transplants were provided in 1970, while the number of transplants was 130 in 1980. The conservative care of renal diseases improved during the 1970s when a new low-protein diet was given in combination with hypertension medication (Kuhlbäck, 2002). The contribution of the renal and transplant patients' association was important in this period. Besides making practical efforts in patient education and media activities to introduce renal diseases to the general public, it proceeded to improve the social position, rehabilitation, and opportunities of care for renal patients (Heinonen & Saloranta, 1995).

The provision of care for diabetes was consolidated in public health care during this period. The State Diabetes Committee published a report in 1976 that became a national program for diabetes care (Tirkkonen, 1998, p. 99). In 1975, there were 100 000 diabetics in Finland, and 80% of them had type II diabetes (Tirkkonen, 1998, p. 95). Health care centers began to develop the organization and practices of diabetes care (Tirkkonen, 1998, pp. 118–119). Social advisors, dietary consultants and physiotherapists were also involved in the provision for diabetes. The care provision included follow-ups, patient education, and consultation conducted by physicians and nurses (Groop, 1978). The self-care done by patients was an important part of the care practice. Opportunities for patients' self-care improved enormously during the 1980s when small testing devices were adopted for patients' use. Drug therapy also improved when new synthetically prepared insulin was adopted for care provision (Tirkkonen, 1998, p. 113). Since the prevalence of type II diabetes had increased in the population, dietary directions and care were re-adjusted (Mäki, 1978; Uusitupa, 1980). In particular, being overweight was emphasized as a critical risk factor for the disease, in addition to elevated serum cholesterol, hyperinsulinism, and hypertension. Active members of the Finnish Diabetes Association became involved in revising the information

concerning diabetes and diabetes care. The association was also active in training patients as well as diabetes nurses.

3.4.3 Challenges in the health care organization for chronic illnesses at the end of the 1980s

In the 1980s, the development of primary health care and hospital care evolved toward more diversification, which resulted in extensive problems of cooperation between different levels (Myllykoski, 1985, p. 917). It was reported that 28.7% of health center physicians did not know about their patients' visits with other physicians, and 14.5% did not even know about a patient's chronic illness (Helenius, Marjamäki, Perkurinen & Vohlonen, 1987, pp. 62–63). Studies on patient satisfaction at this time showed that the patients did not receive proper care. For instance, 11.4% of patients in an interview study reported that they did not receive help for their ailments at a health care center (Helenius & al., 1987, p. 62). Patients with multiple and chronic illnesses were often seen as being demanding and even aggressive (Virta, Makkonen & Rekola, 1980). These patients visited one or more specialties at secondary care. They had made many visits over the course of one year and had sought care for many ailments. The physicians found it difficult to distinguish patients' social problems from the somatic ailments that change from one visit to another (Virta & al., 1980). However, patients with multiple and chronic illnesses were provided care in many locations of care, and none of the providers took responsibility for the overall care (Makkonen, Virta & Rekola, 1980). The lack of patient documentation also increased the difficulty of treating patients with multiple and chronic illnesses (Makkonen & al., 1980). Problems in the accumulation of knowledge as well as in the flow of information seemed to have been a common problem in the 1980s. The patients' documents at the time served the administrative need of gathering information about the use of services and not about the needs in care relationships (Kekki, 1982, p. 2021).

The object of health care organization was, however, worked out on an idealistic level in numerous committees. The overall development of the health care system started as a subprogram of WHO's global health-improvement strategy called 'Health for All by 2000' (Ministry of Social Affairs and Health, 1986). The Finnish subprogram outlined the central visions and aims of the long-term health policy and strategy in Finland. The main points of the strategy included promotion of better life habits, the prevention and removal of health risks, and the development of the health care system as well as the system's effectiveness (Ministry of Social Affairs and Health, 1986, p. 49). The main lines of development focused on the improvement of primary health care. However, a good standard for specialized care was also emphasized, and the principles of shared care between primary

and secondary care were clarified. Furthermore, it was stressed that continuous quality improvement, training of the personnel, and the patient-centered planning of services were to be adopted in health care delivery. Primary health care was restructured to be more humane and flexible. The continuity of care was targeted for more attention, particularly in the provision for chronic patients. The principles of continuous evaluation, overall care provision, and population-based medicine were recognized as developmental challenges of primary care. The aims concerning the development of specialized care related to improved effectiveness, the re-organization of the administration, and the clarification of the central hospitals' responsibility for the overall development in the hospital districts (Ministry of Social Affairs and Health, 1986, pp. 103–117). Disease- and problem-centered plans were also drawn up to outline the object of care provision and clinical practice for certain diseases and health problems in the mid-1970s. For instance, the diabetes, hypertension, and health education committees were such committees (Ministry of Social Affairs and Health, 1986, p. 19).

Challenges in health services lead to improvements at the end of the 1980s. The patients' position improved when a law on treatment injury was enacted in 1986. The law obliged health care centers, hospitals, and other providers to compensate for damages caused by the errors made or injuries sustained during care provision. The re-organization of health care was motivated by the ideal of overall care for patients in primary care and by the better functioning of secondary care. The pilot projects of personally assigned physicians and population-based health services were launched in health care centers (Helenius & al., 1987). Population-based services in primary care were carried out by assigning a population of a certain area to a specific physician. Population-based models were adopted particularly in the largest cities and municipalities, but there was a great variety in locally provided services¹⁹ (Kokko, 1997). A new law carried out the development of secondary care in 1989 and 1991. The new legislation on hospitals included the levels of the university, central, regional, and health-center hospitals. The aim of the enactment was to rationalize the administration of hospital care and its services and to provide new motivation for specialized care delivery for the municipalities in their district. In particular, it was the responsibility of the hospital districts to provide the services that the municipalities were not able to provide or that were reasonable to concentrate in specialized hospitals (Act on Specialized Medical Care 1062/1989). But these changes created a system in which a patient was discharged through many levels involving multiple providers and deficiencies

¹⁹ Kokko estimated that 39–43% of the population was included in population-based responsibility in 1997.

and problems in the responsibility for the overall care (Marjamäki, 1998). For instance, the gaps in the flow of information and in the division of labor between providers have often been reported in the collaboration between primary and secondary care (Nylander & Nenonen, 2000; Karma & Huttunen, 1997).

The expansion of the object of care and the discontinuities between levels and specialties of care emerged as challenges of health care organization in the 1980s. In the 1990s, the increasing complexity of chronic illnesses and the diversity of multiple providers acted as challenges for the health care organization.

3.5 The increasing complexity of chronic illnesses and the diversity of multiple providers: Towards the zone of proximal development

The increasing complexity of chronic illnesses created new demands for health care organization at the beginning of the new millennium. In particular, the multiplicity of illnesses, the aging of the population, lifestyle illnesses, and medicalization have increased the complexity of chronic illnesses. Simultaneously, specialization, market-based development, alternative models of service production, and a new kind of patient agency have increased the diversity of multiple providers in the care of chronic illnesses. From the perspective of a single patient's care, the provision of multiple illnesses is complicated as a result of diverse providers creating a double bind in the care of chronic illnesses. The double bind involves a dilemma related to specialization in medicine. While specialties advance the delivery of chronic illnesses by creating new medical knowledge and skills, they also complicate the care organization when there is not one responsible professional who treats the overall pattern of illnesses (see table 3.1).

From the perspective of activity theory, double binds refer to secondary contradictions in expansive learning that can be solved by modeling a new activity (Engeström, 1987). Activity theory explores double binds as situations in which everyday activities become disturbed by problems, disruptions, and gaps. These discontinuities of activity represent a tension between the prevalent form of activity and developmental challenges emerging in the activity. The collectively generated solutions for double binds potentially embedded in everyday actions represent the possible future forms of activity. Together the disturbances and generated solutions create a zone of proximal development for the activity. The zone of proximal development is defined by Engeström (1987, p. 174) as "the distance between the present everyday actions of the individuals and the historically new form of the societal activity that can be collectively generated as a solution to the double bind potentially embedded in everyday actions." In this subsection, I focus on aspects of the increasing complexity of chronic illnesses and explore

the diversity of health care organization in the 1990s and at the turn of the century. Finally, I outline the zone of proximal development for the provision of chronic illnesses.

3.5.1 The increasing complexity of chronic illnesses

The intertwining of the objective organism, its representations, and the technologies of care make chronic illnesses emerge as complex. The complication of primary diseases often increases the number of multiple illnesses and co-morbidities in a population. For instance, the increase in secondary renal diseases relates to complications from type II diabetes (Stenman & Grönhagen-Riska, 1995). Multiple and chronic illnesses intertwine with each other in a complex manner, requiring a good number of specialized services. For instance, type II diabetes is a multifactor disease with co-emerging illnesses such as heart and renal diseases, and the effective care of type II diabetes involves the adjustment of many body functions, such as the treatment of glucose, hypertension, and hyperlipidemia as well as the prevention of heart infarct (Yki-Järvinen, 1999). Providing care for multiple and chronic illnesses and co-morbidities is also expensive for society and single patients. For instance, the provision for type II diabetes along with its complications and co-morbidities accounts for two-thirds of the total cost of diabetes care in Helsinki (Kangas, 2002). Obviously, patients with multiple illnesses or co-morbidities are not, however, presently identified well enough in the health care organization, which is becoming more diversified due to multiple providers.

The aging of the population along with better living conditions and improved opportunities for treating illnesses also increases the number of chronic illnesses in a person's lifetime. Aging has been estimated to be one of the national challenges for health care delivery in the near future. Luoto & al. (2001) predict that 15% of the male and 20% of the female Finnish population will reach the age of 65 at the beginning of 2010. This is significant for health care organization since people over 65 years of age use four times more health services than people under 65 (Marjamäki, 1998). Consequently, one of the targets in public health policy is to delay the onset of chronic diseases to a later point in a person's lifetime in order to reduce the demands on health services (Luoto & al., 2001).

The prevention of chronic illnesses also further expands the needs for health services. Instead of focusing on single chronic illnesses such as diabetes or heart disease, prevention presently extends to certain life habits that impact chronic illnesses such as overweight, cigarette smoking, and the overuse of alcohol (Puska, 1993). But it is not easy for the 'healthy' to change their life habits before the emergence of illness, or even after the treatment of illness, although the evidence of the connection between unhealthy life habits and certain illnesses is strong,

and illnesses caused by these life habits are serious (Järvi, 2001). Many successful projects such as the North Karelia studies have generated public awareness and knowledge about the connections between high cholesterol and overweight in the incidence of heart diseases and type II diabetes (Puska & al., 1995). But the population seems to be currently adopting more passive lifestyles, which have an impact on the incidence and prevalence of heart diseases and type II diabetes (Airaksinen, 2004). Although the incidence of heart diseases is declining, they are still common and fatal in Finland, and their prevention is considered important along with the development of diagnostics and treatment in cardiology (Airaksinen, 2004). The prevalence of diabetes is also still on the increase in Finland. The number of people with diabetes is presently 180 000. By 2010, the number is estimated to be 300 000, and many people with diabetes have type II diabetes (Suomen Diabetesliitto, 2000).

The prevention of illnesses raises issues related to social life and popular ideas of illness when a large part of the population in the western world is included in prevention programs. Aspects of life such as old age, death, pain, and grief are often labeled and treated as illnesses or diseases (Lahelma, 2003). There is also a danger of 'medicalization' in active prevention when almost everyone receives medication, tests, or treatments for certain organic qualities or body functions (Mustajoki, 2003, p. 1870). For instance, the target values of LDL cholesterol and blood pressure are set in such a way that only a few members of the middle-aged population can be considered healthy (Mustajoki, 2003). The tendency to treat the 'healthy' is making the boundary between what is considered health and what is illness emerge as more vague (Niiniluoto, 2003; Mustajoki, 2003; Lahelma, 2003). The term 'medicalization' often refers to aspects of life that are 'over-medicalized' or exaggerated (Lahelma, 2003). Mustajoki (2003) maintains that 'medicalization' ought to be opposed because it hinders the work of medical professionals, increases the costs of health care, and distorts the idea of illness among the population. Medicalization alongside the development of new medical technologies increases the demands on care by creating new expectations for better care (Niiniluoto, 2003).

3.5.2 The increasing diversity of providers in health care

Specialization, market ideology, standardization, alternative models of service production, and new kinds of patient agency increase the diversity of multiple providers. The growth of needs for services, changes in state subsidies, and the effects of the economic recession at the beginning of the 1990s had an impact on these recent developments.

During the history of providing care for chronic illnesses, professional organizations have increased the diversity of health care organization by accelerating

specialization. The number of specialties and sub-specialties increased to 79 in 1998, but was then reduced to 49 due to EU regulations. The type and quality of specialized knowledge has, however, kept increasing in such a way that some specialties are in fact becoming more internally diversified (Siimes, 2003; also Pylkkänen, 2002). The diversification of specialized knowledge not only concerns increased specialization, but it is also connected to the distinctions between basic and clinical sciences. Medicine is presently dominated by the superiority of the genocentric perspective, while clinical discovery and patient-oriented research have receded from it (Rees, 2002). The role of clinical discovery may even be considered “mere translations of real discoveries made at the bench into the health system” (Rees, 2002, p. 699). But basic research and clinical research are interdependent, and the discoveries of clinical research are also needed to solve the problems of treating complex diseases (Rees, 2002).

A market-based ideology increases the diversity of multiple providers by creating artificial boundaries between public units of provision through the application of management by results approaches in health care organization. Recently, market competition between public and alternative providers has also begun to diversify health care organization. The change in the amendment to the state subsidy system for municipalities in 1993 rendered it possible to make choices between alternative providers (Uusitalo, Konttinen & Staff, 1995). Thereafter, new management models and tools were adopted from economic sciences, such as quality management, cost-effective care, purchaser-producer relations, public-private partnerships, and market competition. Hospital districts as well as private providers began to prepare for competition in the market since they expected municipalities to take advantage of the opportunities to deliver health care with alternative models of service delivery (Jämsén & Pekurinen, 2003).

However, the economic recession at the beginning of the 1990s changed the logic of developing market-based health services. The municipalities did not enter the private markets since recovering from the recession became their main focus. But the recession did not dramatically reduce the standard of services (Uusitalo, Konttinen & Staff, 1995), and the productivity of primary and specialized care even increased during the recession (Uusitalo & Staff, 1997). The structure of the service organization also became more effective when the long-term hospital care of aged, disabled, and mental patients was reduced in the 1990s (Marjamäki, 1998). But the numbers of patients receiving care in primary care increased, however, when the care periods at hospitals became shorter (Marjamäki, 1998). Evidently, the amount of work performed by the personnel increased during the recession, since the number of personnel in health services fell in 1992 and 1993 (Lehto & Blomster, 2000; Marjamäki, 1998). Furthermore, the clients' share of the payment of their health services also increased during the recession (Lehto & Blomster, 2000).

The standardization of health services was another attempt to increase the effectiveness of health care organization. Health care organizations began to implement the Finnish application Diagnosis Related Groups (DRG) for hospital invoicing and the standardization of services in the 1990s (Lauharanta, Virtanen, Rotonen & al., 1997). DRGs had already been in use in the US in the 1960s to support the quality work in hospital wards (Brommels, Virtanen & Liukko, 1998). DRG is “a system for classifying patient care by relating common characteristics such as diagnosis, treatment, and age to an expected consumption of hospital resources and length of stay. Its purpose is to provide a framework for specifying case mix and to reduce hospital costs and reimbursements and it forms a cornerstone of the prospective payment system” (<http://www.dictionarybarn.com/DIAGNOSISRELATED-GROUPS.php>). Presently, the Nordic application NordDRGs is used for the categorization of care episodes and the invoicing of inpatient care in Finland. Other Nordic countries have implemented NordDRGs (Brommels & al., 1998). The adoption of DRGs into the actual practice of providing health care is, however, cautiously proceeding in Finland and needs to be investigated further (Linkola, 2004; Nylander, 1998). “Producing” effective care may lead to providing what is ordered and not what is needed for the care of illnesses and diseases (Nylander 1998, p. 50).

Private providers and public-private partnerships further diversify the variety of health care organization. When the state subsidy system rendered it possible to establish purchaser-producer contracts and partnerships, the private sector showed an inadequate capacity of being able to offer competitive health services, while municipalities also lacked skills for making good use of them (Jämsen & Pekurinen, 2003). Presently, many private providers expand their service by purchasing smaller enterprises and by setting up new businesses. For instance, Mehiläinen Oy (<http://www.mehilainen.fi>) conducted nine purchases in 2003 while at the same time improving its sales 25%. The Pirkanmaa hospital district as a public provider is enhancing its service delivery in collaborative partnerships with other private enterprises. For instance, it provides 1200 operations yearly through the endoprosthesis hospital Coxa (Municipality Periodical, 2004). Correspondingly, the city of Karjaa has purchased health services from the private enterprise Folkhälsan since 1998. The costs of health care for Karjaa have decreased 1.4% from 1999 to 2002, when the average figures of costs show an approximate 12% rise in expenditures in Finland (Tuppurainen, 2003). The services are evaluated to be more effective because the organization of Folkhälsan does not have administrative or other boundaries as the municipal providers. Folkhälsan is able to organize the overall care provision for their customers that influences the total costs of health services. Costs for Karjaa had been rising at the end of 1990. The purchase from the private provider succeeded in cutting down the rise in costs. Furthermore, the city of Karjaa and Folkhälsan are evaluated to have a ‘shared

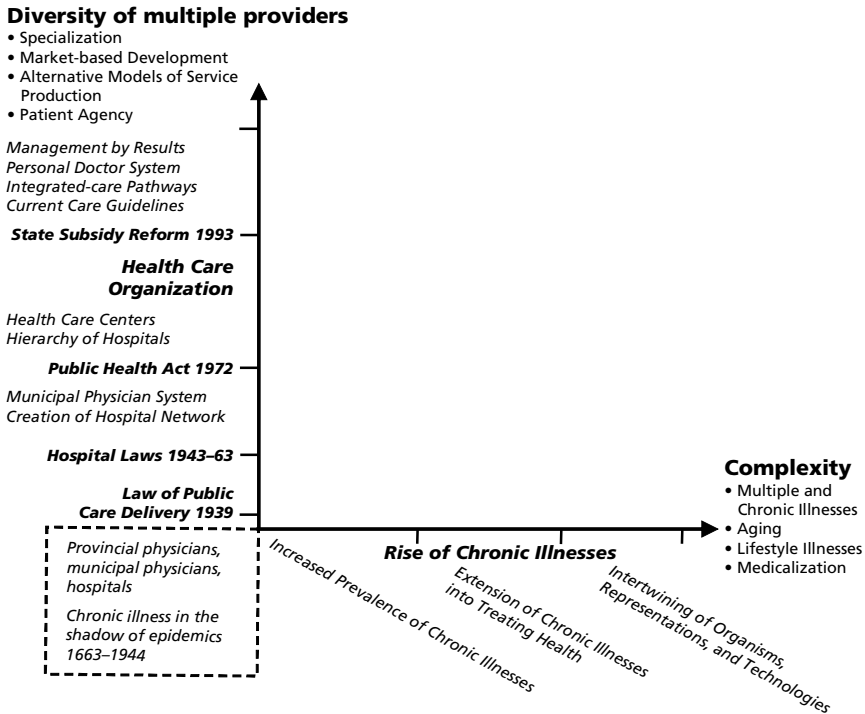
will' on the line of development (Tuppurainen, 2003). The shortage of physicians has lately forced municipalities to hire professional services from temporary service firms. The daily newspaper *Helsingin Sanomat* (Lindberg, 2004) reports on municipalities purchasing medical services for three million Finns from private providers. Most of the purchases are assigned for acute care services.

Changes in patient legislations in the 1990s increased the diversity of health care organization, since patients now should be included in the decision making concerning the treatment of their illnesses. Act on the Status and Rights of Patients in 1992 (Act 785/1992) established the position of a patient. The law gave instructions on patients' rights for good and qualified care, the admission to health services, the delivery of patient files to patients, the autonomy of a patient in terms of treatment and care, complaints regarding the provision, and the system of patient advocacy. However, these norms have not self-evidently guaranteed a more active role for patients (Pekkarinen, 1998). The most recent advancement outlines guidelines for the availability, quality, and sufficiency of care in various parts of the country irrespective of the residents' ability to pay (Ministry of Social Affairs and Health, 2002 <http://www.stm.fi>). The basic premises of the new legislation are access to a preliminary assessment of health within three days of contacting the service, access to outpatient assessment by a specialist within three weeks of receiving the referral, and access to medically justified treatment assured usually within three months and no more than six months after receiving the referral.

3.5.3 Towards the zone of proximal development in health care organization for chronic illnesses

The zone of proximal development depicts a transitional area of change and development between present activity and visions of the future that are generated as solutions for problems, disruptions, and gaps embedded in everyday actions (Engeström, 1987, p. 174). Chronic illnesses presently emerge as complex phenomena involving the intertwining of organisms, representations, and medical technologies. Multiple illnesses, aging, lifestyle illnesses, and medicalization increase the complexity of chronic illnesses, while the health care organization seems to be developing towards a diversity of multiple providers through specialization, market-based development, alternative models of service production, and new types of patient agency. Yet from the perspective of activity theory, the development of the object-creation activity of chronic illnesses and the central activity of the health care organization are interdependent. While the object, the chronic illness, is analyzed as an integral component of the central activity, the health care organization, it is simultaneously analyzed as an independent activity system of its own that is created in medical communities. Figure 3.1 presents the

development of the health care organization and the rise of multiple and chronic illnesses in Finland.



3.1. The development of health care organization and the rise of multiple and chronic illnesses in Finland

The major periods of transition in the central activity, i.e., the development of health care organization, are defined on the vertical axis in figure 3.1. A distinctive law or a reform marks the development leading to a new period. The object-creation activity, i.e., the rise of chronic illnesses due to developments in medicine, is represented on the horizontal axis. The major transitions in the prevalence of chronic illnesses distinguish the phases of object-creation activity in figure 3.1.

In figure 3.2, I depict the care provision for a patient at the crossroads between complexity and diversity. The connecting lines between the horizontal and vertical axes mark the transitions between the new conceptualizations and improved treatments of chronic illness and the societal and organizational processes of change, development, and learning in health care organization. During these processes, new conceptualizations of and treatments for chronic illness are adopted into use in the health care organization. Correspondingly, the development of the health care organization provides opportunities and recourses for the

advancement of medical knowledge in professional communities, which leads to further development. From the activity-theoretical point of view these processes represent transitions between the object-creation activity of chronic illnesses and the central activity of the health care organization.

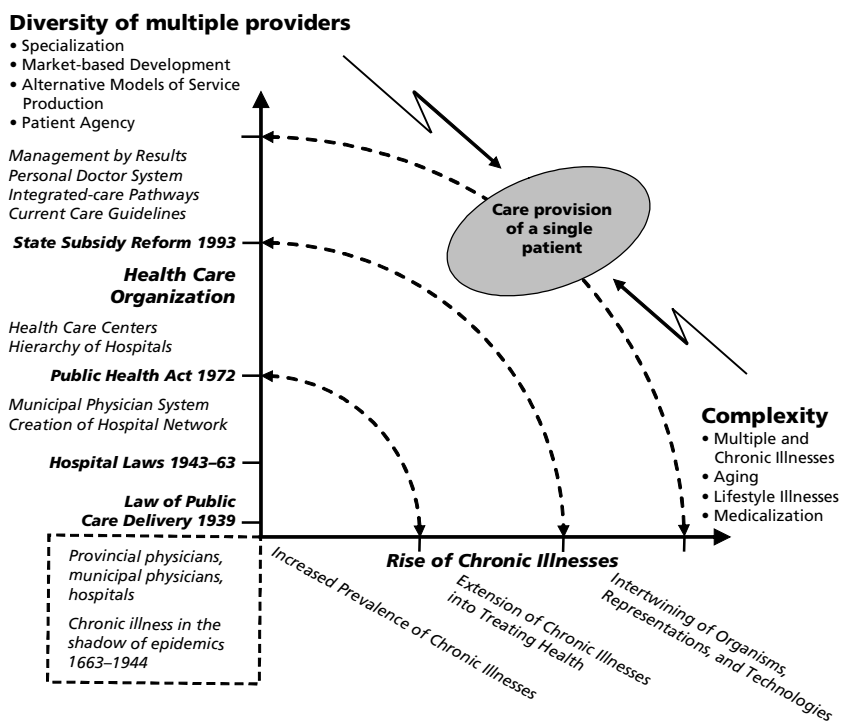


Figure 3.2. Care provision for a patient on the crossroads between complexity and diversity

The development of treatments for chronic illnesses increased the understanding and acceptance of chronic illnesses and diseases as an object of health care during the consolidation of the municipal physician organization and the creation of hospital networks. The development of the central activity of health care organization expanded the provision for chronic illnesses based on specialties while also enabling the development of the object-creation activity of chronic illnesses. During this period, the object of health care organization expanded into treating health, illness, and disease when effective means of curing and preventing chronic illnesses were created and adopted for use in the 1970s and 1980s. In the 1990s, the development of object creation progressed to expanded knowledge and the treatment of chronic illnesses, while health care organization ran into financial and functional difficulties.

The arrows in figure 3.2 represent the contradictions between the ability of medicine to provide care for chronic illnesses and the opportunities for health care organizations to provide care for single patients. A successful provision of a single patient's care does not depend only on the development of diagnostics, care, and treatments, but also on economic and organizational opportunities to provide the care (Huttunen, 2004). Professional authority and systemic hierarchy were previously able to integrate medical discoveries into use, but recent changes in medicine and health care organization position the care of chronic illnesses in a historically new situation in terms of their context and financial limitations. The impacts of these developments especially concern the care of multiple and chronic illnesses, which is becoming fragmented due to the diversity of public and private providers. The provision for these illnesses appears to be fragmented by gaps and overlaps in the care processes and the communication between providers (Engeström & al., 1999; Nylander & Nenonen, 2000; Saaren-Seppälä, 2004).

Future visions for health care organization are presently under public discussion as well as a guarantee of receiving an examination and treatment for illness in Finland. The Finnish Constitution states that the state must ensure sufficient social welfare and health care services for all. The responsibility for arranging the services still lies mainly with municipalities and public providers, but a transition towards more versatile organization is underway. The aim is to develop health services cooperatively between municipalities and the state by taking into consideration the activities of NGOs and the private sector (Ministry of Social Affairs and Health, 2002, p. 11).

Advocates of alternative service production challenge the model of public provision. For instance, Lillrank (2004a, 2004b) emphasizes the productivity of health care organization based on market ideologies such as market competition, laws of supply and demand, productivity, process enhancement, and free choice in seeking service (Lillrank 2004a, 2004b). Lillrank (2004a) accuses the present system of being ineffective. Public health care could cut its costs by 20% by adopting the productivity enhancement found in industry. For instance, Lillrank (2003) refers to the capacity of operation theatres, which could be improved enormously by implementing process enhancement or purchase and storage functions. In fact, the production of health services could, according to Lillrank, be privatized in the long run. The state could regulate and monitor the services, and the municipalities could act as stakeholders on behalf of the Finnish people, who hold the property rights (Lillrank & Parvinen, 2004).

Among the proponents of public health care, Saarelma (2004) shows statistically that future prospects for health care organization were already undermined in the 1990s when the total budgeting for health care favored hospital-outpatient care and privately provided care. However, publicly provided primary care re-

ceives patients whose ailments do not fit into standard forms and who are ‘leftover’ from production-oriented services. The patients suffering from chronic illnesses or multiple problems require longitudinal provision in coordinated networks of multiple professionals.

Saarelma (2004, p. 642) introduces the “standardized service product” model and an alternative model that is based on health care practice. The model of ‘standardized service products’ represents rapidly and effectively delivered services for clients who occasionally seek service for health problems with expectations of quick recovery. An alternative model is based on the continuity of care for patients suffering from multiple and chronic illnesses. The care provision for these patients requires longitudinal care in coordinated networks of multiple professionals. For instance, diabetes or asthma patients represent such patient groups.

In this study, I call the first model the *care package model* and the alternative model represented by Saarelma the *negotiated care model*. Based on these models, I present two choices for the development of health care organization in figure 3.3. The zone of proximal development envisions the future direction of Finnish health care organization.

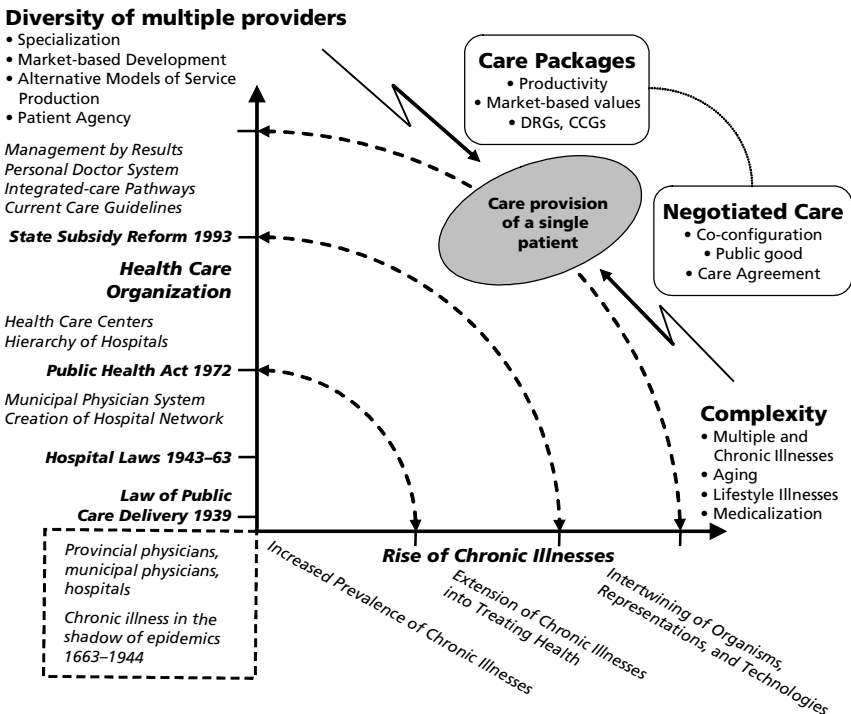


Figure 3.3. The zone of proximal development in Finnish health care organization

The *care package model* is based on productivity, market values, and diagnosis-related groups (DRGs). These issues are currently under a great deal of discussion in academic journals and newspapers. The productivity of health care organization can be achieved by using process enhancement models from industry (for instance, Lillrank & Parvinen, 2004; Lillrank, 2003). For instance, patients can be divided into production lines according to the degree of difficulty of each case. Economies of scale in service production suggest that a production line would function effectively (Savolainen, 2005). Market orientation involves shareholder value, property rights and the client advantage in health care organization (Lillrank & Parvinen, 2004; Lillrank, 2003). DRGs guarantee the comparability of products and provide qualified measures for the evaluation of outcomes and audits in health care organization (Liukko & Luukkonen, 2003). DRGs have the advantage of systematizing health care provision by providing standardized measures instead of measures that are evaluations (Block & Press, 1986). However, the adoption of DRGs may lead to more limited service delivery and the undermining of the societal dimension of health care (Geist & Hardesty, 1992). For instance, the impact of DRGs on hospitals includes the denial of treatment to patients on whom they predict to lose money in the US (Ellis & McGuire, 1986).

The model of negotiated care is based on co-configuration, the public good, and care agreements. Co-configuration represents a historically new type of work that involves the co-constitution of adaptive products and services in continuous relationships between the customer, the product/service and the producer, active client involvement, and the collaboration and interaction between involved parties (Victor & Boynton, 1998). In health care, co-configuration has been introduced as 'knotworking' (Engeström & al., 1999; Saaren-Seppälä, 2004). Knotworking captures the tying and dissolution of collaborative formations in work contexts requiring multidisciplinary practice. Co-configuration guarantees continuity in care relationships that require the coordination of multiple providers and medical specialties.

The ideology of the public good has been one of the 'cornerstones' of Finnish health care. Market-oriented health care threatens, however, the values of the public good. For instance, Jääteenmäki (2004) questions whether health care services can be traded like cars. Production lines in health care may also lead to an emphasis on providing high numbers of care visits for acute ailments like the flu that could be cured by themselves. A focus on providing acute calls also prevents the provision for chronic health problems that often are the cause of acute calls (Lähteenmäki, Vainio & Nurminen, 2005). Productivity measures of health care provision should use the maintenance of health and well-being as their basic criteria instead of using the care visits in care periods as measures of outcomes (Simpanen, 2005).

The model of negotiated care applies a care agreement tool for negotiations between a patient and providers. The care agreement is a signed document that includes the knowledge of a patient's main illnesses or symptoms, the patient's concerns about those illnesses, the information exchange between providers, the division of the care responsibility between providers, and the names and the contact information of all providers. Care negotiation consists of a process during which the overall care of a patient with multiple and chronic illness is secured by locating gaps in the health care organization. The model depicting the process of care negotiation is described in article V (see article V, figure 1, p. 350).

The care package model and the negotiated care model are not likely to emerge as pure, mutually exclusive opposites. A more mixed variety of practices is likely to prevail. The main challenge of future health care organization is, therefore, how to manage the variety of approaches.

The boundaries of health care organization emerge as embedded in the health care provision. They represent the problems, disruptions, and gaps in a single patient's care. The line between primary and secondary care represents the most prominent boundary. In practice it is, however, blurred (Satomaa, 2001), and circumstances, administrative arrangements and a variety of practices determine its nature (Lindén, 2001). The 'old' boundaries between medical specialties and between medical professionals securing the autonomy of a professional also prevail — and are undermined — in present practices.

4 Boundaries in studies of organization, work, and health care practice

4.1 Review of boundaries in studies of organization, work, and health care practice

Boundaries are stable distinctions and differences that groups and human beings create while participating in those activities. The notion of boundaries points to differences and distinctions at work across a wide range of social phenomena, organizations, and institutions. In this chapter, I review how development, learning, and change have been investigated in previous studies of boundaries in organizations, work, and health care practice. The problem is that boundaries are not always explicitly conceptualized in organization studies (Marshall, 2003, p. 56). They are studied as “co-products” of change (Hernes, 2004). Reviews of existing research on boundaries are lacking (Heracleous, 2004, p. 99).

The boundaries of health care are often studied in relation to other research problems, such as division of labor (Allen, 1997; Allen, 2000; Mizrachi & Shual, 2005) or the implementation of new organizational forms (Fulop, Protopsaltis, King, Allen & al., 2005) and technologies (May, Finch, Mair & Mort, 2005). Furthermore, researchers who draw on the concept of a boundary are often unaware of its use beyond their own discipline or even their own specialty (Lamont & Molnár, 2001, p. 168). Given the current stage of boundary studies in organizations, work, and health care practice, I explore these studies at a general level in terms of development, learning, and change.

The investigation of boundaries in studies of organizations and work is currently moving from macro-level perceptions of boundaries as stable and unambiguous to the idea of composite, ambiguous, and permeable boundaries that are constructed in organizational groups (Hernes, 2004). Boundary studies of health care practice illustrate that uniform views on boundaries between professions and organizations of care have been replaced by studies that reveal the diversity and

ambiguity of boundaries in the present health care organization. Regardless of the many studies on boundaries in health care practice, studies on boundaries in the patient experience of health care provision are few. However, all these three areas of study are in the main just beginning to explore the role of development, learning, and change in terms of organizational and practice boundaries.

In the final part of this chapter, three approaches (Scott, Ruef, Mendel & Caronna, 2000; Wenger, 1998; Long, 2001) are selected for the exploration of the development, learning, and change of organizational and practice boundaries. The chosen approaches bring up the macro explanations of change (Scott, Ruef, Mendel & Caronna, 2000) and the micro descriptions of learning (Wenger, 1998) in relation to organizational and practice boundaries. The actor-oriented theory of development (Long, 2001) provides a means of overcoming the macro-micro distinction of organizational and practice boundaries with the opportunities of development in groups and societal movements at social interfaces (Long, 2001). Drawing on ethnographic studies on boundaries and cultural-historical activity theory (Engeström, 1987), I introduce a fourth approach that expands the ideas of the actor-oriented theory of development into the level of organizations and activity. My framework suggests that boundaries are hybrid contexts of the development, learning, and change of activity in work and organizations. Boundaries provide potential for development and change while enabling expansive learning, during which the organizations can contribute to the creation of their possible futures.

4.2 Boundaries in studies of organization and work

Macro-level studies of organizational boundaries originate from general systems theory (Parsons, 1951), contingency theory, and the open system approach (March & Simon, 1958; Lawrence and Lorsch, 1967a; Katz and Kahn, 1967). General systems theory perceives societies and organizations as internally differentiated functional systems and subsystems in interaction with their environments (Parsons, 1951). Hence, a boundary demarcates one social entity from another (Scott, 1998). Boundaries imply discontinuity, which “constitutes a differentiation of technology, territory, or time, or some combination of these” (Miller & Rice, 1967, p. 7).

The boundaries in and between systems relate often to the optimal division of labor that defines the organizational boundaries in complex organizations (Lawrence & Lorsch, 1967b, p. 2). Managers and administrators struggle in order to reconcile the differentiation and integration of major subsystems in turbulent environments (Lawrence & Lorsch, 1967b). Besides physical structures, social struc-

tures consisting of patterned behaviors, reinforced by rules and realized by role behaviors and norms prevail in organizations (Katz & Kahn, 1967). Organizations are both open and closed systems (Orton & Weick, 1990). The openness on the system level is combined with closedness at the subsystem level (Yan & Louis, 1990).

Another macro-level approach is the evolutionary-ecological perspective, which explores processes of change between organizational populations and the institutional environment (Hannan & Freeman, 1989). Hannan and Freeman (1989, pp. 53–54) examine boundaries as segregating and blending processes in the emergence and change of organizational populations. Segregating processes impact the sharpness of distinctions between organizational forms, while blending processes generate arbitrary distinctions between organizations and their environments. Abbot (1988; see also Abbot, 1995a) investigated the professional boundaries of social work from the evolutionary-ecological perspective in public organizations. Instead of seeing the field of professions as being shaped by the inner functions of professional organizations according to the ideas of functionalism, Abbot studied professions as shaped by conflicts over boundaries at the “edges of professional jurisdiction” (Abbot, 1995a, p. 554). When jurisdictional boundaries change, the substance and scope of a profession or occupation also changes (Abbot, 1988). Abbot (1995b) maintained that the creation of boundaries should be explored in action instead of determining them as pre-existing entities. For instance, social work should be studied as a “network approach” arising from a set of “boundary groups,” such as social movements, interest groups, and enthusiastic individuals (Abbot, 1995a).

A third macro-level approach examines firm boundaries and inter-firm relationships between formal organizations and markets (Williamson, 1975), property rights (Grossman & Hart, 1986), networks (Powell, 1990), and resources and capabilities (Teece, Rumelt, Dosi & Winter, 1994). While the conventional approach to firm boundaries is determined by efficiency considerations (Holmström & Roberts, 1998), the capabilities view of the firm suggests that firm boundaries are determined by the relative costs of developing ancillary capabilities as opposed to accessing them through markets (Barney, 1999).

Araujo, Dubois and Gadde (2003) argue that cooperation between markets and hierarchies should be seen as a distinctive coordination mechanism. This idea poses further challenges as to where boundaries should be drawn from a capabilities perspective. The idea of indirect capabilities has been developed to meet the challenges of the embedded nature of the firm’s capabilities for cooperation. Hence, the more firms rely on complex interfirm relationships to access complementary capabilities, the more the boundary of the firm has to expand to incorporate indirect capabilities mutually specialized for relevant partners (Araujo

& al., 2003). Consequently, boundaries provide a space for the development of stable clusters of connections among capabilities within the firm — the buffering function. On the other hand, boundaries provide a bridge enabling access to capabilities outside the control of the firm. Different types of indirect capabilities provide this bridging function while also establishing patterns of connections among distributed capabilities, inside and outside the firm (Araujo & al., 2003, pp. 1270–1271).

A general transition was identified in which the focus of boundary studies changed from the macro or organizational level to the work unit level at the end of the 1980s and the beginning of the 1990s. Organizational restructuring, the increased use of work teams, shrinking organizational slack, workforce diversity, and the adoption of advanced information technology inspired studies on organizational boundaries (Yan & Louis, 1999). The management (the establishment and negotiation) of boundaries is considered necessary to secure their appropriate functioning on every level of an organization (Schneider, 1987). Subjective boundaries at the level of individuals and groups had already become, however, an interest of organizational psychologists in the 1950s and 1960s. Trist, Jaques, Menzies, Rice, and Miller argued that when people face uncertainty and feel at risk, they set up psychological boundaries based on anxiety-reducing tasks that violate pragmatic boundaries (Hirschhorn, 1988, p. 32). If boundaries are inappropriately drawn, they impact people's ability to accomplish their tasks. The task of the managers is to draw and maintain appropriate boundaries between the organization and its environment (Hirschhorn, 1988, p. 38).

New ideas about subjective boundaries are presently emerging in an organizational reality that is becoming increasingly “flat,” “lean,” and “fragmented” (Hirschhorn & Gilmore, 1992). The traditional boundaries of hierarchy, function, and geography are disappearing, giving way to the idea of “boundaryless” organizations. The authority boundary, the task boundary, the political boundary, and the identity boundary represent new boundaries, as suggested by Hirschhorn and Gilmore (1992).

Product development teams have proved to be a fertile ground for studying the activities that the teams use to manage their organizational environment beyond their teams (Ancona & Caldwell, 1988; Ancona & Caldwell, 1992; Ancona, 1990). The transactions between internal and external activities are secured by the group roles of scout, ambassador, sentry, and guard (Ancona & Caldwell, 1988). The results of the study indicate that teams engage in vertical communications aimed at molding the views of top management and horizontal communication aimed at coordinating work and obtaining feedback in parallel with a general scanning for technical and market environment demands (Ancona & Caldwell, 1992).

Team boundaries are also explored in the transformation of a commercial lending institution from a functional to a team-based structure of organizing (Cross, Yan & Louis, 2000). The transformation was examined temporally and in terms of three aspects of boundaries, including the boundary of spanning, buffering, and raising up boundaries. Yan and Louis argue (1999) that boundary activities are not eliminated as a result of organizational changes. Organizational restructuring and system transformation increased the permeability of both intra- and inter-organizational boundaries. However, the challenges and hazards created in adopting new organizational forms and the associated change processes did not receive sufficient attention in the organization (Cross & al., 2000, p. 860).

Recent technological developments, the globalization of markets, and the transition from mass production to other forms of production have raised a need for organizational boundaries to be rediscovered and re-specified (Hernes & Paulsen, 2003). The boundary itself has become a center of interest. Contingency theory and new institutionalism perceived boundaries as stable and unambiguous. However, studies investigating the dynamics and complexity of contemporary organizations can hardly rely on assumptions of stability and equilibrium (Hernes, 2004). Hernes (2004, p. 10) argues that boundaries are not by-products of organization, but that organizations evolve through the processes of boundary setting. Boundaries are intrinsic to organizations, and organizations operate simultaneously within multiple sets of co-existing boundaries. Boundaries are reproduced through interaction, based partly on past experiences and partly on changes within the environment. Hernes (2004, pp. 12–13) suggests that boundaries should be differentiated according to the governing mechanisms of “what goes on inside them” and suggests a framework for studying mental, social, and physical boundaries as ordering, distinction, and threshold mechanisms. Mental boundaries describe “the particular repertoire of terms and symbols that enable groups to communicate, act, and to further their understanding” (Hernes, 2003, p. 40). Mental boundaries guide organizational actions (Hernes, 2004, p. 14). Social boundaries refer to the creation of “otherness” in social interaction. Physical boundaries refer to the materiality of boundaries (Hernes, 2003, p. 40).

But studies of the formation, properties, and consequences of boundaries as complex, shifting, and socially constructed entities are still few (Heracleous, 2004). Current developments in boundary studies reflect, however, a change in the research focus towards boundaries at the practice level, which can be seen in the edited volume of Paulsen and Hernes (2003). Consequently, studies on organizational development and learning are also moving away from the reconciliation of organizations and environments by creating functional structures, routines, rules, and roles “within” an organization to “learning together” at the “border interfaces” of an organization (Holmqvist, 1999). The link between boundary

studies and processes of learning has, however, been weak, and it is important to integrate processes of learning into studies of organizational change and development at the boundaries. Next, I turn to the level of health care practices to explore how boundaries are investigated in day-to-day practice.

4.3 Boundaries in health care practice and patient experience

The dominant subject of boundary discussions is the division of labor in the health care context (Allen, 2000). Boundaries between professions (Svensson, 1996; Allen, 1997; Allen, 2000), specialties (Hibbert, Hanratty, May, Mair & al., 2003), general practice and pharmacy (Mesler, 1989; 1991), and biomedicine and alternative medicine (Mizrachi & Shuval, 2005; Mizrachi, Shuval & Gross, 2005) are examples of such studies. The creation of new organizational structures (Fulop, Protosaltis, King, Allen & al., 2005) and technological solutions in organizational activity (May, Finch, Mair & Mort, 2005) reflect the challenges that recent developments in medicine and technology and the increasing number of chronic illnesses raise for boundaries in health care organizations.

Nurses crossing occupational boundaries are a common topic in studies of health care practice (Allen, 2000, p. 330). The special knowledge of professions and occupations demarcates boundaries between professionals and laymen, general and specialized knowledge, and between specialties (Freidson, 1970; 1988; 2001). In practice, it is, however, sometimes impossible to draw clear boundaries between the 'medical' and the 'nursing fields' (Svensson, 1996). In order to address how social order such as division of labor is maintained and changed in practice, Strauss, Schatzman, Ehrlich, Bucher, and Sabshin (1963) introduced the term "negotiated order" to emphasize that ambiguities inherent in organizations require negotiation in order for organizational work to take place (Maines, 1982, p. 269). "The negotiated order perspective attempts to show how, on the one hand, negotiation contributes to the constitution of social orders and, on the other, how social orders give form to interaction processes including negotiations" (Maines, 1982, p. 275).

Allen (1997; 2000) explores the ambiguities in the negotiated order between doctors and nurses in micro-sociological studies of health care practice. The work of nurses is expanding into tasks that before were the responsibility of physicians, while changes in the professional hierarchy also impact the division of labor between physicians (Allen, 1997). Doctors accept changes in what they regard as 'low status menial activities,' but hesitate to give up more focal tasks of medicine such as diagnostic investigations (Allen, 1997, p. 504). In practice, nurses blur the traditional doctor-nurse boundaries informally when doctors are not pre-

sent (Allen, 1997, pp. 511–512). Nurse managers seem to adopt similar discursive practices and rhetorical devices for making distinctions between nurses and nurse support workers than doctors use to distinguish their work from nurses' work (Allen, 2000). These distinctions are based on the idea that expertise and professional knowledge is considered to be distinct from the technical type of work typical of a lower level of the professional hierarchy (Allen, 2000, p. 349). The realization of negotiated order was found to be ambiguous in studies of the nurse-doctor boundary. Allen's observations revealed little evidence of actual negotiations of division of labor in practice. The findings of Allen's study also show that division of labor can be modified without face-to-face negotiations (Allen, 1997, pp. 514–515).

Hibbert and his colleagues (2003) provide an example of how medical specialization is realized in professional discussions within medicine. The example investigates the expansion of traditional palliative care (end-of-life and cancer) into a new field of palliative expertise in cardiology. The creation of expertise is explored in a single specialty and comprised general practitioner focus group discussions. The study reveals how palliative medicine and palliative care are two polarities set between symptom-focused, technical medicine and indeterminate, 'holistic' care. Symptom-focused, technical boundaries emerge as more coherent and are more difficult to contest than those of 'holistic' and 'psychosocial medicine.' However, the relationship between the shifting views of expertise and the ideas about how services should be developed is considered complex, and the distinctions between professionals are subtle (Hibbert & al., 2003, p. 286).

The exploration of professional boundaries at the outset of biomedicine and alternative care (Mizrachi & al., 2005) represents a further example of boundary setting in professional and societal discussions. Economic factors and market conditions enabled the introduction of alternative practitioners to hospitals in Israel. Mizrachi and his colleagues (2005) explore the tacitly marked boundaries between biomedicine and alternative medicine as a discursive field in day-to-day hospital work. The study indicates how biomedicine secures its boundaries in collaborative processes of boundary demarcation between biomedical and alternative professions and how alternative medicine is legitimized in the hospital by informal rather than formal processes. Biomedical providers occupy leading positions while alternative practitioners take secondary positions in the interactions with patients. Furthermore, alternative care reserves external locations (at the end of a corridor) or margins of the hospital (an outside building on the periphery of the hospital complex) (Mizrachi & al., 2005).

The formal level of discourse documented in official statements brings up, however, a more distinctive positioning between biomedicine and alternative medicine than that of day-to-day practice (Mizrachi & Shuval, 2005). The bio-

medical discourse seeks to secure its dominant position by drawing strict cognitive and moral lines differentiating “proper medicine” from “improper alternative medicine.” At this level, alternative medicine appears morally “contaminated” and its knowledge base delegitimized by extreme forms of boundary work. Modifying the forms of boundary work appears to be biomedicine’s reactive strategy in a field of changing environmental and market demands that allow biomedical discourse to absorb its competitor within its professional jurisdiction with no battle, while retaining absolute epistemological hegemony and institutional control (Mizrachi & Shuval, 2005).

Recent challenges of organizing more effective health services have led to the re-creation of new organizational structures in health care. Fulop and her colleagues (2005) study contexts and processes of organizational change as a longitudinal process in provider mergers in the NHS, England. A merger is conceived of as a process with ambiguous boundaries (Langley, 1999). The first part of the study explores the stated and unstated ‘drivers’ of change in documents and interviews, while the second part of the study, which builds on the first part, investigates four in-depth case studies of the merger process in the second and third years post-merger. The findings of the study show that mergers are usually based on simplistic notions of organizational change and do not expound on the dynamics involved in the relationships between the organization, the context, and individuals. Organizational cultures emerge as barriers in bringing organizations together. The study reports little evidence of achieving the economic and clinical objectives that act as drivers for a merger.

Rodríguez, Langley, Béland, and Denis (2003) investigate the forces that promote or hinder the development of collaboration across organizational boundaries in a top-down managerial intervention in Canada. The conceptual framework of the study involves a focus on mandated collaboration as a non-voluntary process according to which members of an organization do not necessarily perceive their interdependence ‘a priori’ the intervention. The dynamics of the collaborative process are also perceived as political, e.g., the evolution depends on the power, values, and interests of the participants. Furthermore, the collaboration is approached as regulated by multiple governance mechanisms. The findings of the study indicate that emerging forms of collaboration are strongly determined by underlying patterns of power dependencies, values, and interest. The prevailing hierarchies support a simultaneous value system in health care. Incentive mechanisms that stimulate interest in collaboration and bureaucratic mechanisms such as the standardization of processes and outcomes facilitate the initiation of mandated collaboration. Power, values, and interests influence the emergence of forms of mandated collaboration both directly and indirectly.

Qualitative studies reporting on patients' experiences of illnesses have a long history in medical sociology, as was illustrated in chapter 2 (for instance, Bury, 1982; Charmaz, 1983; Williams, 1984) and medical anthropology (Kleinman, 1997). A few studies (for instance Strauss, 1984; Strauss, Fagerhaugh, Suczek & Wiener, 1997/1984; Engeström, 2003) deal, however, directly with patients' experiences of health care organization. Thorne's (1993) study is one of the few that describes the patient experience of health care organization. Thorne (1993, p. 129) reveals that the social context of chronic illness involves a "head-on collision" in the encounters between patients and a health care system. Patients easily "fall through the cracks" due to these collisions. Health care organization is "a revolving door of specialists and services without anyone willing to make a commitment" (Thorne 1993, p. 133). Patients are in danger of drifting from one provider to another without any of them being a primary source of care. They can also fall between the mandates of various government ministries (Thorne 1993, p.134) and find themselves "getting caught in red tape" while regulations within the health care system, bureaucracy, and turf battles create boundaries in care practice (Thorne 1993 143–145).

The multiple ways in which information technologies are currently being deployed provide some insight into the extent to which existing boundaries in health care are being put under pressure. The transition from using technological innovations in telemedicine and tele-healthcare systems to management systems in the distribution of health care suggests that boundaries will grow even more blurred in the future (May & al., 2005). May and his colleagues explain these changes by drawing on a series of earlier studies exploring the development, implementation, evaluation, and experience of telemedicine systems in clinical practice in the UK (May & al., 2005, p. 1487). The merging boundaries of the information age represent the challenges created through information technologies in health care organization. While telemedicine enabled the rapid sharing of information in tele-radiology and tele-dermatology, tele-healthcare services can be used to perform triage on patients and define their clinical trajectory before providing for them in conventionally organized pathways of care (May & al., 2005, p. 1490). Hence, the real shift in tele-healthcare is in the territories in which tele-healthcare is carried out. The distances that are bridged by technology are no longer within formal institutions of the health care system but between a patient and a provider (May & al., 2005, p. 1491). Monitoring units reading data outputs and call centers employing protocol-driven nursing services provide some of the services in health care. Both patients and professionals become reconfigured, and the division of labor extends into more fine-grained areas in health care (May & al., 2005).

New technologically mediated health care provision has been claimed to distance patients (May & al., 2005). May and his colleagues maintain that it is not

the provision of health care that needs to be modernized but also the users of these services. However, distancing the patient from their providers seems unsettling since the care provision involves other aspects of care than medical tricks on organs. For instance, being ill is often connected to complex situations and relationships in a patient's life-world that require sensitivity from a provider of care organization in order to promote recovery and to invite a sense of agency in the patient (for instance, Katz & Shotter, 1996).

The discussions of health care boundaries include alternative views on what the future of health care organization will be. Many boundary studies in health care practice describe aspects of change and development, but the idea of change is often explored as an effect of development outside the health care organization. Studies exploring learning are implicit and seem to be confined to socialization of boundaries in professional activities (for instance Allen, 1997) or the adoption of boundaries during changes in health care organization (for instance Fulop & al., 2005).

Recent boundary studies in organizations and work indicate a growing interest in the processes of development, learning, and change taking place during boundary setting (Paulsen & Hernes, 2003). In the following section, I explore three approaches to boundaries (Scott & al., 2000; Wenger, 1998; Long, 2001) in order to investigate boundaries and their processes of development, learning, and change at the organizational, workplace, and group level. Finally, I present the fourth approach of this study.

4.4 Four approaches to organizational boundaries

Scott and his colleagues provide a historically based image of institutional change and the reasons behind why change happens (Scott, Ruef, Mendel & Caronna, 2000). Boundaries are, however, depicted as emerging as a co-product of change and development while learning is not discussed. The theory of situated learning in communities of practice (Wenger, 1998) provides descriptions of learning on the micro-level of boundary processes and practices. The actor-oriented theory of development (Long, 2001) is introduced as a means of connecting the macro and micro processes of boundaries. However, Long focuses on boundaries on the level of groups and social movements, while the level of activity is also investigated in this study. The fourth approach of this study expands the ideas presented by the actor-oriented theory to the level of activity in work and organization. Figure 4.1 presents the four approaches and their connection to the study of boundaries.

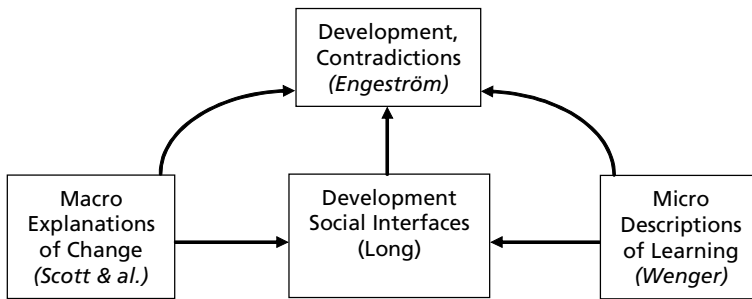


Figure 4.1. Four approaches to the study of boundaries

4.4.1 Boundaries as criteria of institutional change in health care organizations

Scott and his colleagues (2000) integrate ideas from rational, natural, and open-system approaches in organization theory in order to investigate change in organizations and institutions that interact with their environments. Boundaries are considered as important criteria of institutional change in terms of changes in the organizational populations and fields (Scott & al., 2000, p. 91). Boundaries are investigated as outcomes of processes and forces that cause boundaries to erode while other forces such as stable technologies and strong regulatory systems work to maintain the boundaries (Scott & al., 2000, pp. 15–16). However, the focus is on the institutional transformation above the level of the individual organization (Scott & al., 2000, pp. 10–14).

Their case study represents an analysis of the institutional change in health care in the San Francisco Bay Area in the US from World War II to the present based on archival data, historical information, and survey data (Scott & al., 2000, pp. 55–56). Health care organizations are perceived as rational, normative, and open systems possessing resources, rights, and distinctive capabilities. Organizations and organizational populations are constituted of material-resource environments (demand-side factors, supply-side factors, and technologies) and institutional environments (regulative, normative, and cultural-cognitive structures) that operate to provide coherence, meaning, and stability to the field (Scott, 1995). In institutional environments, institutional logic, institutional actors, and governance systems are important. Institutional logic involves the field's organizing principles that are available to organizations and individuals as material practices and symbolic constructions to be elaborated. Institutional actors function as carriers and creators of institutional logic (Scott & al., 2000, p. 20). Governance systems are arrangements that exercise control and power over actors (Scott & al., 2000, p. 21).

Changes in organizational boundaries in organizational populations mark the rise and fall of specific organizational forms. The erosion of boundaries over time is documented as evidence of boundary confusion. For instance, integrated health care systems as an emerging organizational form are presently difficult to define when some systems are integrated horizontally, some vertically, and others by virtual ties. The changes in field boundaries involve a transition from traditional forms of the professionally dominated service sector to cost effective and managed health care services. Scott & al., (2000, p. 357) maintain that the erosion of the ideological barriers that secured the traditional services became delegitimated and discredited by the fragmentation of existing governance structures, both professional and public, enabling a new logic of limiting professional privileges. The diverse interests of the specialists and the growing number and diversity of public regulatory systems had an effect on the erosion of traditional organizational forms. The weakening of the professional association together with increases in health care costs made it possible to introduce new sets of logic and governance mechanisms. This change was accelerated by the packaging of managerial logic as a new and effective set of tools for public policy.

Scott and his colleagues provide an image of institutional change that emerges as an outcome of historically evolved relationships, the logic of actions, material environments, and populations. Why change happens is clarified but the role of boundaries is not clear in practice, as boundaries emerge as co-products of change. The findings of the study are based on archived traces of change and development in documents. Documents do not necessarily reveal the level of practices in action, although they may act as containers of past activities (Prior, 2003). The participants in the organizations, however, often pay attention to the behavioral criteria of organizational boundaries, as Scott and his associates (2000, p. 355) also point out.

4.4.2 Boundaries as elements of learning and interpretation in social practices

The theory of situated learning views learning as participation in social practices (Wenger, 1998, p. 3). Communities of practice are created by “shared histories of learning” involving the mutual engagements and joint enterprises of individuals who are learning while engaging in and contributing to the practices of their communities (Wenger, 1998, p. 86). Boundaries are useful for communities of practice because they can offer opportunities for unusual learning from diversity and different perspectives (Wenger, 2000, p. 233).

Communities of practice are separated by boundaries and peripheries. Boundaries refer to discontinuities and lines of distinction between the inside and outside of a community, while peripheries represent continuities, areas of overlap,

and connections (Wenger, 1998, p. 120). Peripheries emerge in regions that are neither fully inside nor fully outside and surround the practice with a degree of permeability (Wenger, 2000, p. 103). In practice, boundaries and peripheries are interwoven. The boundaries of communities of practice are not necessarily congruent with the institutional boundaries of which the community of practice is a part. Yet they are not independent of institutional boundaries either. Compared to institutional boundaries, boundaries of communities of practice are fluid and often unspoken (Wenger, 2000, p. 232).

Boundary brokers, boundary objects, and boundary encounters ensure the continuity between diverse communities of practice. Certain members of the community, such as boundary spanners, roamers, outposts, or pairs, can act as boundary brokers. Some objects can also act as boundary objects (Star & Griesemer, 1989). Boundary objects can be artifacts (tools, documents, or models), discourses (the existence of a common language), or processes (routines and procedures) (Wenger, 2000, pp. 235–236). In boundary encounters, members of different communities can create an arena for mutual engagement. When such encounters become established forms of interaction between communities, new practices are likely to emerge, and the boundary practice may become a more stable form of brokering (Wenger, 1998, p. 114). Communities of practice may act as a bridge between institutional boundaries because they represent boundaries on the level of everyday activities in which the motivation to get things done may sometimes run ahead of “bureaucratic rigidities” (Wenger, 1998, pp. 118–119).

The negotiation of meanings is an important element in Wenger’s theory of situated learning in communities of practice. “Practice is a process by which we can experience the world and our engagement with it as meaningful” (Wenger, 1998, p. 51). The empirical data that Wenger (1998; 2000) uses to explore the characteristics of communities of practice is based on an ethnographic study in a medical claims processing center of a large insurance company in the US. The negotiation of meaning involves two constituent processes that Wenger calls ‘participation’ and ‘reification.’ For instance, according to Wenger (1998, p. 55), “The [claim] processor as a member of a community of practice embodies a long and a diverse process of what I [E.W] will call *participation*.²⁰ Similarly, the claim as an artifact of certain practices embodies a long and diverse process of what I [E.W] will call *reification*.²¹ It is the convergence of these two processes in the act of processing the claim that the negotiation of meaning takes place.” Thus, ‘participation’ describes the active involvement of members of a community of social enterprises on the experiential level, while ‘reification’ in Wenger’s usage captures the process

²⁰ Italics E.W.

²¹ Italics E.W.

of giving material form to our experience.²² For instance, tools, symbols, stories, terms, and concepts are such objects that practice has reified during the history of participation in communities of practice (Wenger, 1998, pp. 58–59).

In Wenger's theory of communities of practice and situated learning systems, the dynamics of change, development, and learning are, however, in danger of becoming reduced to interpretations and negotiations of meaning driven by individuals' motivations in communities of practices that are facing 'forces from the outside' as 'contexts of negotiation.' On the other hand, Wenger (1998, p. 73) acknowledges that the association of practice and community requires a more precise concept of practice "by distinguishing it from less tractable terms like culture, activity, or structure." The connection between communities of practice and macro-level structures and their development through learning remains, however, unclear while the interpretation and negotiation of 'outer realities' and contexts may only renew present practices and organizational hierarchies in work units.

4.4.3 Social interfaces as arenas of development in social change

The actor-oriented sociology of development represents a social constructionist view of change and continuity as opposed to structural, institutional, and political economy analyses (Long, 2001). It attempts to explore how the analysis of small-scale interactional settings can be integrated with larger institutional social structures in developmental interventions involving groups and social movements.

The actor-oriented sociology of development conceptualizes boundaries as 'social interfaces' that "explore how discrepancies of organizational interests, values, power, and division of labor are mediated at critical points of linkage" (Long, 2001, p. 50). Interfaces involve discontinuities in interests, values, and power, and their dynamics entail negotiation and struggle over definitions and boundaries (Long & Villareal, 1993, p. 143). The actor-oriented sociology of development explains how the products of social action, such as policy documents, technologies, commodity markets, or socio-demographic patterns, are constructed socially and culturally. Interfaces typically emerge at the intersections of different and conflicting life-worlds, organizational fields, or institutional domains and arenas of social action (Long, 2001, p. 65). Therefore, social interfaces are composed of a certain degree of discursive hybridity. One of the major tasks of the interface analysis is to bring forth multiple discourses and their power implications involved in the social reality that is under study.

²² As Wenger (1998, p. 57) himself maintains, his formulation of *reification* is more general than those of Marx and Lukács, who characterize the process by which social phenomena appear to be factual in ways that hide their social production and reproduction.

Long's actor-oriented sociology grew out of the studies and debates in rural development studies that Norman Long and his wife Ann carried out in Peru during the 1970s. In those studies, the effects of 'macro' theories in rural development were challenged 'from below' in 'micro' studies where a network of interrelations between production, trade, transport, peasant agriculture, and the provincial urban economy were consolidated over a period of time (Long, 2001, pp. 22–23). Later, studies conducted in Mexico enriched the conceptualization of social interfaces (Long 2001; also Long & Villareal, 1993). Interface analysis has also influenced the idea of planned social change or 'planned intervention' in rural development. Interventions (and also change in general) cannot be preplanned but emerge as ongoing interactions and socially constructed processes and may have unexpected influences on social structures (Long, 2001).

Social interfaces integrate interactional 'micro' processes and societal 'macro' processes in social encounters and struggles. Long (2004, p. 28) maintains that social interface "forges a theoretical middle ground between so-called micro and macro theories of change by showing how interactions between 'intervening' parties and 'local actors' shape the outcomes of particular intervention policies, often significant repercussions on patterns of change at regional, national and even international levels." Long makes a conceptual distinction between 'social fields,' 'domains,' and 'arenas' that influence the conceptualization of social interfaces. The notion of a 'social field' refers to products of human and non-human interventions resulting from social action at the intersection of different social domains. 'Domains' are areas of social life that are organized around central core values. 'Arenas' are social locations or situations (Long, 2001, pp. 58–59). Actors' projects are realized in specific arenas and fields of action. Continued interaction encourages the development of boundaries and shared expectations that shape the interaction of the participants so that over time the interface itself becomes an organized entity of interlocking relationships and intentionalities (Long, 2004).

The concept of 'human agency' has a central position in actor-oriented sociology of development for theorizing the 'macro' and 'micro' elements and processes. "The notion of agency attributes to the individual actor the capacity to process social experience and to devise ways of coping with life" (Long, 2001, p. 16). Social actors possess capabilities for problem solving, and they actively engage in constructing their own social worlds (Long, 2001, p. 24; see also Giddens, 1984, pp. 1–16). While an individual person is most often referred to as a human agency, social agency can be embodied, for example, in enterprises, agencies and political parties.

By acknowledging the existence of multiple social realities, the actor-oriented sociology of development questions at the same time the ontological realism of positivist science. It conceptualizes knowledge as involving ways of constructing

and ordering the world, not just as a simple accumulation of facts or as being unified by some underlying cultural logic, hegemonic order, or system of classification (Long, 2001; Long, 2004). Neither does the actor-oriented theory of development remain in the position of an interpreter of complex realities. Instead it emphasizes the potentialities of human agency in constructing and transforming those realities. However, the actor-oriented theory of development does not have the concept of contradiction as a driver of change in development. Furthermore, the actor-oriented theory of development does not discuss learning or take potentialities of learning into account. Through learning, it is possible to expand the prevailing realities by creating new instrumentalities and opportunities for action argues Engeström (2001).

4.4.4 Activity-theoretical framework for the study of boundaries in work and organizations

Activity theory approaches learning, development, and change as intertwined in everyday practices (Engeström, 1987). The individual actions and interactions of an activity are carried out in local contexts that make use of historically available resources in the construction of emergent realities and futures. However, the construction of realities is not only discursive. It involves the creation of new instruments that enable the emergence of qualitatively new objects and forms of activity as solutions to the internal contradictions of the previous activity (Engeström, 1987, p. 144; see also Engeström, 2000b; Miettinen and Virkkunen, 2005). The concepts of cultural-historical mediation and the object-tool relationship in developmental and learning processes are important starting points for the framework of studying boundaries in health care organizations.

Signs and tools deriving from local histories and cultures *mediate* human actions (Vygotsky, 1978, pp. 53–54). Rules, communities, and division of labor also act as mediators of human actions (Leont’ev, 1978). Boundaries are often considered as endpoints of activity, where the cultural and social mediation stops or changes into another form of mediation (Alvarez, 1995, p. 452). However, border studies in social anthropology suggest that besides discontinuity, life at the borders also involves continuities, cultural and social bonds, and networks (Alvarez, 1995, p. 462; Lightfoot & Martinez, 1995, p. 474). Besides separating different social worlds, boundaries can also unite them (Alvarez, 1995; Lightfoot & Martinez, 1995). Hence, boundaries can act as mediators of cultural and social formations, networks and practices. Single cultures have their historical origins as well as exchanges and networks between cultures (Lightfoot & Martinez, 1995). Boundaries can, therefore, display “situated histories in action” that can be traced as “tradition sources” in the present (Hyysalo, 2004, pp. 48-50/Renvall, 1983, p. 199). Be-

sides presents and pasts, boundaries can also act as temporal carriers of imagined futures by making the disturbances and tensions of the ‘normal’ practices and conventions visible and by providing for instrumentalities that enable possible futures (Engeström, 1999a, p. 178; R. Engeström, 1999b). Future-oriented mediations are not, however, carried out for their ‘own sake,’ but they are carried out ‘for’ something. Activity theory suggests that this ‘why’ of action is its collective object and motive.

Objects and motives are implicitly included in activity, and they emerge and change in artifact appropriation (Leont’ev, 1978, p. 52). Objects are, therefore, open-ended material and social projections oriented to something that does not yet exist (Engeström, 1995a). An object can simultaneously be an object of activity or its means, e.g., tools in human activity (Rheinberger, 1997, pp. 28–29). During tool creation, an object becomes materialized in object-tool transitions, e.g., an object of a group becomes a tool for another group, and later an element of the entire activity system (Miettinen, 2005, pp. 61–62; Miettinen & Virkkunen, 2005). In activity-theoretical studies, object-tool transitions are made visible in interventions aimed at expansive learning and development. The ideal-typical model of an expansive process involves epistemic learning actions of questioning, analyzing contradictions historically and empirically, modeling a new solution to solve the double binds emerging in an activity, examining the new model, implementing the new model and reflecting on the process, and consolidating the new practice (Engeström, 1999b, pp. 383–384).

Boundaries create, however, situations in which tasks at hand challenge practitioners to negotiate and combine ingredients from multiple and often parallel activities with distinctive objects (Engeström & al., 1995; Engeström & al., 1999; Lambert, 2003; Tuunainen, 2004). Gutiérrez, Baquedano and Tejada (1999) call such locations “third spaces” in which the exploration of alternative and competing discourses and positionings are enabled in educational practice. A third space is also considered a site “in which the object of an activity is extended and the activity itself reorganized resulting in new opportunities for learning” (Gutiérrez & al., 1999, p. 287). Hence, a third space represents a hybrid learning environment that is polycontextual, multivoiced, and multiscripted and which originates from diverse cultural sources.

The Change Laboratory resembles a ‘third space’ in which the emerging new activity of negotiated health care provision is created at the boundaries of the dispersed and fragmented activities of health care organization. However, unlike ‘third spaces’ that focus on education and community, actions and interaction at the Change Laboratories emerge as situational collaborative formations of participants that are driven by tasks and objects at hand in work activity. In the Change Laboratory, the practitioners experiment with the new tools (i.e., the care calen-

dar, care map, and care agreement) in the care of their patients. The Change Laboratory emerges, therefore, as a particular type of discursive hybridity that captures the heterogeneous, overlapping activities, their mixed repertoires and collective interpretations (R. Engeström, manuscript). Change Laboratories temporarily expand by creating a zone of proximal development in the interaction that is realized when participants look back at the history of their activity and engage in future-oriented experiments (Engeström, Engeström & Kerosuo, 2003).

In work activities requiring negotiation and the integration of multiple activity systems, the spatial and temporal expansion of object (Engeström, Puonti & Seppänen, 2003; Hasu, 2000) seems particularly important from the perspective of this study. The object connects the multiple activity systems. The focus on development, learning, and change expands the investigation of the object into the developmental and learning activity in this study. At the Change Laboratories, three different activities in terms of the object emerge: (1) the practical activity of a single patient's care in which the object is a pattern of diseases, illnesses, or symptoms, (2) the developmental activity in which the object is the emergent new framework of work in the health care organization, and (3) the reflective learning activity of the participating patients and professionals in which the object is the emergent work practice (see R. Engeström, manuscript). The constellation of activity systems presented earlier in figure 1.2 is now modeled to include the learning activity and the developmental activity that take place at the Change Laboratory (figure 4.2). The model represents the framework of this study.

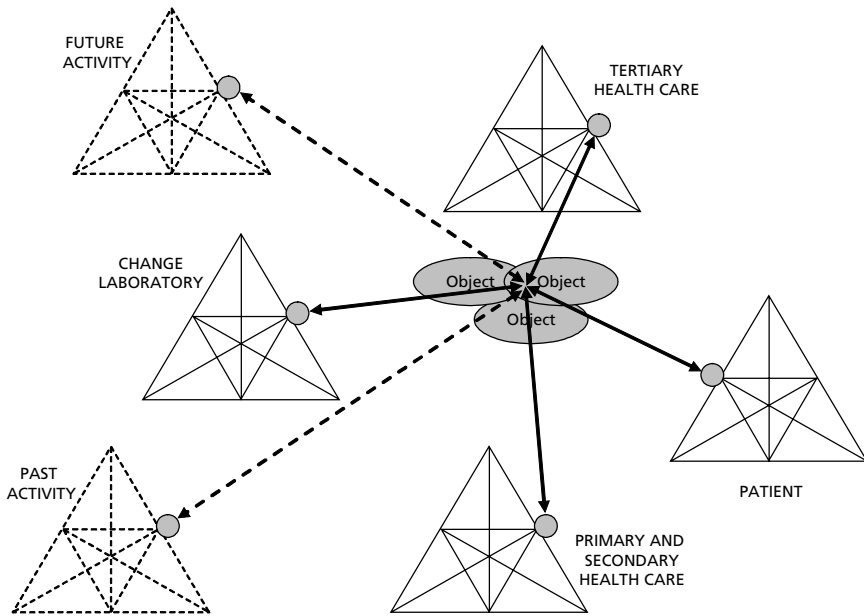


Figure 4.2 The framework for studying boundaries and boundary crossing in health care

The health care organization, i.e., the practical activity, includes the activity system of the primary and secondary health care, the activity system of tertiary health care, and the activity system of a patient with multiple illnesses. The activity system of the Change Laboratory represents the development and learning activity that emerges in connection to the practical activity. The practical activity, learning activity, and developmental activity emerge as intertwined, and they are connected to past and future activities.

Participants in the Change Laboratory bring with them various institutional affiliations, rules, and resources that create heterogeneity in multi-organizational practices. The encounter between the diverse systems emerges as a 'border zone.' Studies in social and cultural anthropology highlight the blurred nature of 'border zones' emerging between distinctive cultures (Rosaldo, 1993; Lightfoot & Martinez, 1995). However, 'border zones' "should not be regarded as analytically empty transitional zones but as sites of creative cultural production that require investigation" (Rosaldo 1993, p. 208). In this study, 'border zones' are explored in terms of development, learning, and change at the boundaries in the multi-organizational field of health care organization. The developmental and learning processes of the Change Laboratory create a 'border zone' that involves hybridized behavior, conflicts and contradiction, and the reconfiguration of social patterns in the multi-organizational encounters (Alvarez, 1995, p. 462).

Lotman (1990, p. 125) displays a semiosphere as a semiotic space of culture that is marked by its heterogeneity, including the diversity of elements and their different functions. A 'semiosphere' is characterized by the dynamics inherent in the relationship between the center of the semiosphere and its periphery. The most developed and structurally organized forms of culture constitute the center of the culture, while the periphery is constituted by the heterogeneity of the culture. The boundary is the 'outer limit' of the semiosphere, which generates new forms of culture by translating the external elements of the 'other' into culture (Lotman, 1990, p. 131). The semiosphere is, therefore, in constant movement between the 'culture' and the 'non-culture.' The 'periphery' may move into the center and the center can be pushed out to the periphery. The development is intensified in these 'frontier zones of culture' (Lotman, 1990, p. 141).

Besides cultural change, the movement between the cultural center and periphery also characterizes developmental and learning processes at the 'border zones.' Hence, the stable state of an activity system may be conceived of as 'culture,' while 'non-culture' emerges as more blurred and contradictory, both promising and threatening. The zone of proximal development displays the area of change that can be achieved during expansive learning and development.

The hypothetical zone of proximal development of this study was historically outlined in chapter 3. The 'border zone' may now be defined in developmental terms. It is the distance outlined by the zone of proximal development between the known past 'culture,' the unknown 'non-culture,' and the imaginable future 'culture.' The 'non-culture' emerges in the developmental and learning processes at the boundaries of the dispersed activity systems. Figure 4.2 as a whole represents the 'border zone' in this study.

5 Methodology, method, the research process, and data

5.1 Ethnography of a multi-organizational field of activity

Methodology is the general approach for studying a research topic, as distinguished from methods that are specific research techniques (Silverman, 1993, p. 2). The methodology of this study is the ethnography of a multi-organizational field of activity that draws on anthropological methodology and cultural-historical activity theory.

Anthropology represents a comparative study of a particular social and cultural environment that uses fieldwork as its primary source of new knowledge (Eriksen, 1995, p. 4). Traditionally, the topic of anthropology was meant to provide a full description of a people under study and their way of life. The method of studying was to go and live among the researched subjects, which were most often primitive people, and the product of the study was a holistic description of their way of life (Marcus, 1998). However, ethnographies that investigate the 'globalized world,' e.g., migration, international companies, epidemiology, environmentalism and toxic disasters, journalism, and developmental studies just to name a few, can no longer focus on the single-sited research ideals of classical anthropology; the concept of multi-site ethnography seems more proper (Marcus, 1995; Hannerz, 2003). Marcus (1995, p. 95) defines multi-site ethnography as a movement "out from the single sites and local situations of conventional ethnographic research designs to examine the circulation of cultural meanings, objects, and identities in diffuse time-space" (Marcus, 1995, p. 96).

In this study, discussing the organization of care for patients with multiple and chronic illnesses in the context of global ethnography may seem perhaps a little far-fetched at first sight. However, a patient with multiple and chronic illnesses is no longer a visitor of one clinic or one practitioner, but the health care system 'multi-locates' them into dispersed sites with rules, referrals, and professional practices.

Multi-sited ethnography as advocated by Marcus (1998) does not, however, pay enough attention to history, change, and political issues (Gille, 2001). Gille calls for a more open-ended ethnography where the site is produced in concrete local struggles and becomes transformed as the history unfolds (Gille, 2001, p. 321).

Applied ethnography is a practically oriented approach that attempts to influence change and decision making among those who are participating in the study (Chambers, 2000). Applied ethnography resembles developmental approaches in cultural-historical activity theory with regard to its orientation to practice and participation in change processes. The focus of developmental work research on disturbances and troubles is also similar to applied ethnography. In “developmental ethnography” or the “ethnography of trouble,” researchers are involved in interventions that make the disturbances of the work practice that are under investigation visible (Engeström, 2000a; Helle, 2000). However, activity theory searches for the origins of change in historically accumulated contradictions and participates in designing change in future-oriented developmental interventions (Engeström, 2000a). Recent activity theoretically oriented ethnographies of change and intervention expand the focus of study into the entire process of development (e.g., Hasu, 2005; Helle, 2004). In this study, the entire process of development, learning, and change is also brought forward in order to capture the dynamics related to the multi-organizational activity in health care organization.

The ethnography of a multi-organizational field of activity makes connections and disjunctions between multiple locations of care a research object. In anthropology, border studies and contact theories focus on border regions and inter-cultural encounters in zones of cultural interfaces (Lightfoot & Martinez, 1995). These cross-cutting and overlapping social units can be defined and recombined on different spatial and temporal scales of analysis (Lightfoot & Martinez, 1995, p. 472; see also Alvarez, 1995 for ‘borderlands’). Rosaldo (1993) calls these kinds of blurred spaces border zones, which are investigated as contested areas of change between distinctive cultures in social and cultural anthropology. In this study, the focus on border zones brings up aspects and processes of the development, learning, and change taking place at the boundaries of the multi-organizational field of health care.

5.2 The ethnographic fieldwork of the study

Ethnographic fieldwork usually implies a long-term stay in the field. In applied ethnography, long-term fieldwork is often replaced by brief ethnographic visits. Such ‘rapid’ or ‘step-wise’ ethnography is aimed at solving particular research problems posed by an ongoing research project (Chambers, 2000, p. 863). In activity-theoretical studies such as this one, the ‘ethnography of change’ (Hasu, 2001; 2005) and

the 'ethnography of intervention' (Helle, 2004) represent 'step-wise' ethnographies that follow the processes of change and development. These ethnographies are interested in exploring critical aspects of activity in terms of development, learning, and change instead of describing the *status quo* of an activity (Hasu, 2001).

Marcus (1995) suggests six strategies for constructing a multi-site ethnography: follow the people, follow the thing, follow the metaphor, follow the plot, story or allegory, follow the life or biography, and follow the conflict. Usually, an ethnographer doing multi-site research chooses between or creates a combination of these strategies. In my study, the six strategies are combined and extended from their original description provided by Marcus (1995). The ethnography here is about 'following patients' and their life histories of illness and disease that were represented in their interviews. The 'object' of health care, i.e., an illness, is also traced in its multiple locations of care. Furthermore, I have added the strategy of 'following the practice' suggested by Strauss (2000, p. 181). In her effort to understand yoga in its transnational context, Strauss became largely involved in a process of following the history and social life of a set of practices (2000, p. 181). The local history of the health care organizations and the treatment of diseases and illnesses proved also to be important in my study for understanding the 'macro-interdependencies' that were 'inescapable' from the perspective of a single patient in treating multiple and chronic illnesses (Rabinow, 1986, p. 181).

Ethnographic fieldwork traditionally involves an eyewitness researcher who intends to capture the life of the field in a form that is as 'true' as possible. Critical self-reflections in ethnography have led researchers to speak about the 'truth' of the research subject as an outcome of interaction or even of collaboration between research subjects and researchers (Angrosino & Mayas de Pérez, 2000, p. 675). Instead of being an observer of reality, the ethnographer constructs reality on the basis of his or her interests (Marcus, 1998). However, the ethnography of a multi-organizational field of activity is not only interested in sharing knowledge about the research subject, but as Gupta and Ferguson (1997, p. 39) suggest it is also interested in forging links between different types of knowledge.

An ethnographer needs to be sensitive to the conditions of his or her own participation as a part of doing ethnography (Davies, 1999, p. 73). In this study, the researcher is collaboratively 'seeking traces' of the patients' multi-locale care with the patients and the professionals that are involved in their care. Hasu (2005) emphasizes the importance of the phenomena that seem invisible and fragile in the examined activity. The ethnography of the multi-organizational fields in this study is also engaged with the fragility of development. However, the durability of the collaboration, as well as the involvement of the research subjects, becomes even more fragmented and transient in this study compared to Hasu's study on multi-site ethnographies such as this one. There are no 'real natives' sharing ex-

periences and collectivized understanding on longitudinal bases, and the ‘natives’ are perhaps more like ‘strangers’ as researchers (Hannerz, 2003, p. 210).

5.3 The research process and my method of tracing

The ethnographic process often comprises the following phases: preliminary preparations, access and the initial encounters, data collection, recording, reflecting, analysis, and writing (Delamont, 2004, pp. 223–227). I describe the research process by making use of my field diary.

5.3.1 Getting ready for the research project

The preliminary preparations for my research project were carried out collaboratively within the intervention project. The preparations involved the planning and negotiations with the management and representatives of the participating health care organizations. I also visited some principal specialists in specialized care and senior physicians at the community health centers. These visits gave me some basic information about the specialties and health care centers involved in the project. I obtained documents such as administrative plans and reports from the organizations, which were then used to create knowledge about the local health care organization. I also read the literature and earlier studies dealing with the problems in the present health care organization in order to gain a general idea of what I was going to study. However, it was difficult because I did not exactly know what I was getting involved in.

During the preparatory period, the health care management of the primary and specialized care selected the group of patients with multiple illnesses for the study. The internal medicine specialties that participated were cardiology, endocrinology, pulmonary diseases, rheumatology, and renal diseases in secondary and tertiary care. Then the health care management from both organizations assigned medical professionals to the project from primary care or from one of the chosen specialties in secondary and tertiary care. The medical professionals selected single patients for the project among their patients. Their criteria for the selection was that the patients were willing participants, that they have multiple illnesses, that they live in a certain area of the capital region, and that the professional had assessed that their care involved problems of collaboration. After the patients for the study had been selected, the researchers and in some cases also the professionals who had made the selection contacted the other care providers of the selected patient. The ethnography involved 26 patients with multiple illnesses who received care in the capital area of Finland.

As Delamont (2004, p. 224) suggests, I started writing up my preliminary ideas about the fieldwork. My field diary and the first published article (article I) present my preliminary ideas. My “foreshadowed problems” involved the idea that Change Laboratories were like ‘borderlands’ (see article I p. 55). There were boundaries in the health care organization that influenced the care of patients with multiple illnesses. The boundaries could not, however, be observed clearly, and I suspected that there were multiple boundaries interwoven in action. I decided to call that area of multiple simultaneous boundaries in change a ‘border zone.’ A ‘border zone’ refers to areas of ‘no-man’s land’ in health care organization that are located between the organizational boundaries (see article I p. 57). I did not know, however, what the boundaries and border zone were in practice. I knew that there was a boundary between primary and secondary care, but I did not know what it was, how it affected the patients’ care, and why it was there. I started as a ‘naive ethnographer’ since I had only common sense knowledge beforehand about the field I was going to study.

5.3.2 Construction of the multi-organizational field of activity in patient cases

The construction of the multi-locale care organization began with following the life history of the patients and health documents. As Strauss, “I found myself following threads and trails of people, publications and practices that together told the story” (Strauss, 2000, p. 163). The process of fieldwork included selecting the patient with the help of a professional, meeting the patient, tracing the crucial care providers named by the patient, accompanying a patient in his or her visits to medical providers, and getting the patient’s documents from the local health clinic and hospitals. Getting the professionals to choose the patients was not easy. In fact, it took two months of persistent contact with many units of care in order to get the name of the first patient. One patient’s case is presented as an example and I am using my notebook as a source for the description of the case.

Tommi’s case as an example

On the 24th of February, 2000, there is an entry note in the field diary about the first contact with the GP: “*I talked with Marian (GP) today on the telephone, she is really busy, but she had gotten the names of two patients. She promised to phone them next week.*” And then, on March 2 Marian called at about eight in the evening and said that she had found two patients who had agreed to participate in the project, a man with diabetes and a woman with arthritis. I received permission to get in touch with them. The first contact with Tommi was on the telephone the next day. According to my notebook, I learned that apart from diabetes, he also suffered from heart insufficiency. At that time, we had several patients whose care was being traced.

Tommi's interview took place on March 16 at his home in the afternoon. The notebook gives the following account: "*The patient has visited many places of treatment in specialized care. Problems with the flow of information! Significant, the patient's own role in his care.*" I was surprised that no one was in charge of the overall care of the patient but Tommi himself. In the interview, we gathered information about Tommi's illnesses, the locations of his medical care, the flow of information, and the division of care responsibility. Tommi also gave the names of the professionals who were treating him in different locations.

I had an interview with Marian on March 27. She had chosen Tommi because she wanted to find out more about this patient whom she had rarely met with face to face but whom she had consulted with quite often on the telephone. Tommi gave me permission to see his documents and to make copies of the documents showing the contacts between him and the GP. Marian felt that the most acute problem was the flow of information between the different parties of care. The division of care responsibility also remained unclear.

The other interviews in Tommi's case were not easy to arrange. The telephone numbers of the professionals can change, and the professionals can be transferred to other locations, so they were difficult to contact. The entry from March 24 says: "*I also tried to reach the diabetes doctor from the city hospital, but he was on vacation.*" On March 27: "*The diabetes doctor answered the telephone in the middle of a patient consultation. We agreed that I should call again in a quarter of an hour, but the line was then busy.*" I managed to talk with him the next day and we agreed on an interview on April 7. On that same day, I had a conversation with Tommi. "*He said, he still has problems with breathing during the nighttime. He says that nothing is happening on the lung side or in cardiology. He might want to see a private doctor, because Tommi himself knows exactly what might help. Now, he is not getting much sleep. We also talked about his appointment at the cardiologist's on April 14. I will try to be there.*"

On March 31, I dedicated the whole day to making contact with the professionals connected with several patients. I made a call to the hospital wards at the specialized hospital in order to identify everyone who had treated Tommi during his several ward periods. Tommi's documents could not be obtained because they were in another ward. I had to ask for them on another day, which I did on April 3. The documents were available to be seen on April 4, when I was myself sick. The other researcher in the project retrieved the papers, and we acquired the names of the specialists who had been treating Tommi.

On April 7, I seemed to be having a busy day, which was a rule at that time. I was working with a number of cases. At first, I tried to reach some of the specialists responsible for Tommi's care at the specialized hospital. I reached one of them and agreed on an interview. The other two specialists could only be reached

on April 10 and 14. I found out the name of the cardiologist whom Tommi was supposed to meet on April 14. He could be reached on the 11th. On the same day, April 7, I finally interviewed the diabetes doctor at the city hospital. Then I continued with Tommi's case by interviewing the two cardiologists and the specialist in lung diseases. I consulted the kidney specialist by telephone and interviewed the diabetes nurse on the phone. After this, the senior researcher of the project and I accompanied the patient to see his cardiologist, and had an interview with him as well as with the patient. I also collected the case documents from every location.

After gathering the data, the research group held a meeting to choose the relevant parts of Tommi's care that would be presented as a "mirror" in the Change Laboratory, which took place on April 18, 2000. The Change Laboratory meeting is described in article I. The difficulties in reaching the various parties of Tommi's care depict the dispersed character of the care. How can a sick person manage to visit so many different locations for care, when even the researcher had such a hard time reaching everyone?

In order to make sense of the complicated care arrangements I was encouraged to draw maps in the research group. Examples of the care maps are shown in articles I and II (see article I, p. 60 and article II, p. 42). According to Marcus (1995, p. 105), multi-site research is about making chains, paths, treads, conjunctions, or juxtapositions of locations that represent the connections among sites as well as the logic of making the connection. (See for instance, Tommi's care map, which is depicted in article I.) On the maps I depicted the different locations of care, as well as the care providers and the dates of the visits. The patient's list of diseases and symptoms determined which locations were included in the map. I also marked the connections between the locations. The connections were formal, e.g., information on the referral note or care feedback. Many times, when I went for a doctor's consultation, the documents had not been transferred. Therefore, in most cases, the patient himself was the one who knew the connections. As a researcher involved in this project, I also knew more about a patient's care in other locations than the professional I was interviewing.

5.3.3 Data and recording

The data collection was carried out in two phases following the schedule of the intervention project. During the first phase of the project in 2000, the fieldwork included observation of 16 patient cases. Each case contains interviews with the patients, interviews with the care providers, a collection of the patients' medical records from all their providers, and patients' visits with the doctors, as described in Tommi's case in the previous section. Recorded and transcribed Change Laboratory sessions with the related documents and the data used as the basis of reflec-

tion in the Change Laboratory sessions are also included in the data. However, in the cases of six patients a laboratory session was not arranged.

During the second phase of the project in 2001, a pilot group of thirteen medical doctors and three nurses applied the care agreement and the new additional tools (the care calendar and care map) to the care of their patients. The data of the patients collected during this phase includes the meetings between a member of the pilot group (a medical doctor or a nurse from primary or specialized care) and a patient, other meetings arranged by the professionals, and the Change Laboratory meeting. The data was recorded on audiotapes and in most cases also on videotapes. A research assistant transcribed almost all the data. The primary care documents and hospital records of every patient are also included in the data. The correspondence between the pilot group members and the researcher are also kept as additional research data. A field diary was kept during the research process. The research data of this study is summarized in table 5.1.

Table 5.1 The research data of the study

Type of Data	Number
1. Observation	
– Field diary pages	184
– Patients' visits with doctors	18
– Patient interviews conducted by medical doctors	6
– Planning meetings between the providers and the researcher	5
– Care negotiations between providers	3
– Care calendar document	20
– Care map document	20
– Care agreement document	7
2. Interviews	
– Researcher's interviews with patients	31
– Researcher's interviews with single providers	74
– Follow-up interviews with patients or their representatives	16
	Total 121
3. Change Laboratories	
– Implementation laboratory sessions 2000	10
– Change Laboratory sessions 2001	9
– Concluding seminars 2002	3
	Total 22
4. Patient Documents	
– Primary care 2000	226 pages
– Secondary care 2000	548 pages
– Private providers 2000	3 pages
– Primary care 2001	17 pages
– Secondary care 2001	10 pages
	Total 854 pages
5. Correspondence	
– Patients' care provision	
– Change Laboratory meetings	
– Concluding seminars	
– Steering group meetings	
– Researcher group	
– Other	
	740 messages
6. Other data	
– Interviews with single representatives of the health care organizations	14
– Information meetings for personnel	3
– Steering group meetings	15
– Researcher group meetings	43

The observations of this study involve a mixture of observing and interviewing (see Eriksen, 1995, pp. 25–26). During the first phase of the project, the overall organization and pattern of the care were observed. Going along with the patients on visits to their physicians provided information on and revealed the atmosphere of the care organization. Informal talks with patients on the phone, in waiting rooms, and during treatments illuminated the patients' feelings about their care provision. Talks and e-mail messages with the professionals in the process of trying to reach

them for interviews gave information about their situation. During the second phase of the project, researchers observed the professionals' interviews with their pilot patients and the care negotiations between providers in the process of experimenting with the new tools. Some professionals also invited the researchers to share their reflections on the experimentation and arranged 'planning meetings' with the researchers. Informal contact with the professionals and their patients at the hospital and Change Laboratory locations increased our knowledge about the health care organizations and care provision. Observations were recorded in the field diary, patients' care calendars, care maps, care agreement forms, audiotapes, video, and e-mail messages. The field diary preserves my observations at the research sites and also serves as a record of interaction (which is not tape-recorded or videotaped) between different actors participating in patient care. It also contains a daily memo of the fieldwork. The notebook is handwritten in diary form. It involves 184 handwritten pages. These observations are used as additional resources in the analyses of the interviews and laboratory sessions.

My method of interviewing followed the principles of interactionism (Silverman 1993), active interviewing (Holstein & Gubrium 1998), and ethnographic interviewing (Davies 1999; Sherman Heyl 2002). Interviews varied from 'semi-formal guided conversations' to 'free-flowing informational exchanges' between the interviewee and interviewer (Holstein & Gubrium 1998). The present study contains three kinds of interviews with the patients. The first type, the initial interview before the Change Laboratory, includes a loose description of a patient's illness history, his or her present illnesses, and the problems and developmental challenges of health care observed by the patient. The second type of interview is the feedback interview after a reception with a medical doctor. The third type of interview, the evaluative interview, contains a patient's depiction of the care as he or she felt about it after the Change Laboratory. Patient interviews are also the main source of the data in article III.

The interviews with professionals can be divided into initial, informative, and feedback interviews according to the type of contact with them. In the initial interviews, the medical professional who had selected the patient for the project described the patient's illness history, present illnesses, and problems in the care provision. The informative interviews involved information concerning a patient's present care provision and/or information received from other providers. These interviews were carried out with the initial contacting of professionals and other providers. Feedback interviews were carried out after the patients' visits with their doctors and included information related to the patient's visit.

During the second phase of the project, the interviews between the professionals constructing a patient's case and the researcher resembled planning meetings. In these, the professional and the researcher discussed and planned the construction

and preparation of the patients' case. During the second phase of the study, the members of the pilot group also conducted interviews (see Engeström, Engeström & Kerosuo, 2003). The professionals were provided with a list of interview themes that they could use if they considered it necessary. Most professionals used the lists. In two out of ten cases, the professional did not conduct the interview with his or her patient but asked the researcher to conduct it.²³ The professionals' interviews are analyzed as secondary data for the care calendars and care maps in articles I, II, and IV.

Change Laboratory data includes recorded interactions from the laboratory sessions. During the first phase of the project, ten Change Laboratory sessions called Implementation Laboratories were arranged. The care calendar and care map were developed as additional tools to report the pattern of a patient's care provision. The challenges and problems of the provision expressed in interviews and other data were presented on videotape as a base for reflection, i.e., the "mirror," for the patient and the participants in the sessions. During the second phase, nine Change Laboratory sessions were arranged. The first session was a preparatory gathering in which the process was negotiated with the participants and the findings of the first phase were presented. The eighth and the ninth session concluded the process and involved reflecting on the experiments with the new tools. The pilot-group members discussed their patient cases in six other meetings. The pilot-group member whose patient case was discussed presented the information related to the patient case with the help of the care calendar and care map (see Engeström, Engeström & Kerosuo, 2003). The researchers analyzed the observational data that was gathered during the professional's experimentation. This preliminary analysis was presented with the help of video clips in the Change Laboratory session. A research assistant transcribed the recorded sessions verbatim. Examples of Change Laboratory data are given in articles I, II, III, IV, and V.

Patient documents were gathered from all locations of a patient's care during the first phase of the project. Patient documentation includes patient files from community health centers and hospitals, referrals from community health centers to hospitals, and care feedback information from hospitals to health centers. The documentation was used to get an overall picture of a patient's care history (the care calendar) and locations of care (the care map). During the second year, a member of a pilot group assembled a patient's care history and the locations of care. The research group collected the documents provided by the member of the pilot group. These documents are used as additional resources in the analyses of the interviews and laboratory sessions.

²³ One patient interview was conducted during the patient's normal visit with the doctor. One patient interview was not documented. These are not counted as interviews.

Correspondence between pilot group members and the researcher includes the e-mail messages that were received and sent during the intervention project. The participants of the intervention project and the researchers exchanged information concerning the laboratory sessions, concluding seminars, steering group meetings, and patients' care provision. In the first phase of the project, messages were sent when the medical doctors chose the patients for the project. During the second phase of the project, a member of the research group and the researcher exchanged information on the patient cases. This correspondence is used as an additional resource in the analyses of the interviews and the laboratory sessions.

Other data gathered in the project contains interviews with single representatives of the health care organizations, information meetings for personnel, steering group meetings, and researcher group meetings. This data is tape-recorded and used as additional resources in the analyses of the interviews and the laboratory sessions. All research group meetings were not, however, recorded, or even documented. For instance, the research group meetings before the Change Laboratory sessions were not documented. These are not counted in table 5.1.

The research data was arranged as units of patient cases. One unit includes all the data gathered in one patient's care. Table 5.2 presents an example of one patient's case.

Table 5.2 The data of Patient 'Tommi'

Patient	Observation	Interviews	Patient Documents	Change Laboratory	Follow-up interview
Patient 5, Male, 63	Field diary The patient's visit with the cardiologist at the university hospital 14.4.2000	<ul style="list-style-type: none"> - The patient 6.3.2000 - The patient 14.4.2000 - General practitioner at the primary care 27.3.2000 - Internist at the secondary care 7.4.2000 - Clinician at the university hospital 11.4.2000 - Cardiologist at the university hospital 14.4.2000 - Pulmonary specialist at the university hospital 14.4.2000 	<ul style="list-style-type: none"> - Health center 18 pages - Secondary care hospital 8 pages - University hospital 184 pages 	18.4.2000	The personal doctor 5.3.2001

The types of data in table 5.1 and 5.2 are used in the following way. Article I investigates one patient case, Tommi's case, while articles II and IV investigate another patient case, Mark's case. Other patient cases are not included in this study. Article III examines patients' experiences of health care and uses the patients' interviews as primary data. The researcher's interviews with the patients, the follow-up interviews with the patients or their representatives, and the patient interviews conducted by medical doctors are included in the analysis. Articles V and VI investigate the data gathered during the second phase of the project in 2001. The data is explained in more detail in the articles.

5.3.4 Methods and the proceedings of the data analysis in the included articles

The method of selecting the cases in articles I, II, and IV was based on the choice of a typical example of a patient's care organization. Tommi's case was selected for the first article because it also represents other cases in terms of the fragmentation of care provision, the problems in the information exchange between providers, and the lack of the overall responsibility for the patient's care. Tommi's case was also chosen because it was the first one discussed in the Change Laboratory sessions.

The criterion for selecting Mark's case for the analysis in articles II and IV was that his case represents the first session (session five in 2000) in which the care agreement was discussed and agreed upon.²⁴ The types of interactions in Mark's case were also repeated in the Change Laboratory sessions during the first year of the intervention project.

Articles III, V, and VI represent more focused research topics than the previous articles. The choice of the topics results from my deeper involvement with the field of the study. In article III, patients' interviews were chosen for the analysis to represent the patients' perspective of their care provision. The patients' perspective of health care is an important topic, but only few studies deal directly with those kinds of experiences.

In articles V and VI, the data gathered in the second phase of the project was selected for the analysis in order to investigate the boundary dynamics during the creation and experimentation of new communicative tools and practices. Article V examines the expansive learning in the process of creating and implementing new tools and tool use for the inter-organizational care provision. Article VI explores the process of creating a new sense and meaning for the inter-organizational care provision during the Change Laboratory discussions.

Units of the analyses can also be divided into two sets in the first and the second phase of the study. Articles I and II investigate the 'border zone' and boundar-

²⁴ However, the care agreement document was not used, even though the researchers encouraged it.

ies in actions and interactions. The unit of ‘border zone’ is used to capture the multiple boundaries in motion as an area of change and learning in encounters at the boundaries (see article I, p. 57). In article II, a ‘boundary encounter,’ i.e., the border zone, is investigated in ‘discursive boundary actions’ (see article II, pp. 39–40). The unit of ‘discursive boundary action’ describes the historical dependencies and imagined futures in human actions that are discursive by nature (R. Engeström, 1999b; Engeström, Engeström & Kerosuo, 2003).

Article IV investigates the boundaries at the activity (system) level, the action level, and the level of operations. Providers from different health care organizations represent the organizational boundaries in their interaction. Deriving from the history of health care, the activity-level boundaries are frames of reference for (inter)actions and operations. The unit on the action level of activity consists of the sub-units of maintaining, questioning, and transforming the boundaries in the interaction of the laboratory session. The unit on the operational level of the activity studies is the ‘landmark of boundaries’ in the interaction (see article IV, pp. 174–177). The ‘landmarks of boundaries’ are also studied in more detail in article II (see article II, pp. 43–44).

The second phase of the project applies more specific units of analyses. Article III investigates the patients’ experiences of ‘being orphaned’ and ‘being abandoned.’ The context that frames the individual experiences is the multi-organizational context of health care and the reported experiences express the boundaries of the activity. Therefore, boundaries are examined as boundary effects in the article.

Article V investigates the tool creation and implementation in inter-organizational care in the unit of ‘boundary crossing’ (see article V, pp. 346–347). ‘Boundary crossing’ occurs when a member of a pilot group uses or elaborates on the new tools to interact with a professional from another level or division of health care organization.

Article VI examines the discursive space in inter-organizational interaction as a ‘social-organizational interface’ (see article VI, pp. 4–6). Inter-organizationally provided care produces interfaces that emerge between providers in their everyday practices and intersections. The disjunctions emerging in the interaction between providers and patients show the points of tension in social-organizational interfaces. A disjunction emerges in the interaction when a participant of the laboratory session (a patient or one of the providers) observes that a relevant part of a patient’s care provision is being neglected.

Proceedings of the data analysis in the included articles. The first article provides an ethnographic description of the multi-organizational field of activity of one patient’s case. It also provides a description of learning at boundary encounters. The overall constellation of the care for a patient with multiple illnesses and the learn-

ing process of a boundary encounter at the Change Laboratory were described using the data from one patient's case.

Article II investigates the linguistic means of expressing boundaries and their connection to activity in social interaction. First the 'landmarks of boundaries' were identified in speech turns. Secondly, the expressed boundaries were traced in relation to health care provision. The elements of an activity system were applied to outline the connection between the expressed boundaries and the practical activity. Thirdly, two specific situations of the boundary encounter were identified in the transcript as examples of a boundary encounter.

The analysis of one implementation laboratory session in article IV was completed in five steps after transcribing and dividing the data into utterances. At step one, the utterances were grouped following the phases of discussion, and the 'landmarks' of boundaries were marked in bold on the transcript. In step two, the categories of boundary expressions were traced by following the 'landmarks.' The boundary expressions were then grouped into three categories. Step three was to repeat the categorization of boundary expressions in order to make sure of the interpretation of the expressions. In step four, the boundaries expressed in the discussion were adjusted for the boundaries emerging at the activity level by relating each boundary expression to the analytical tool depicting the activity level. Finally, in step five the analysis at the activity level was completed in order to illustrate the present stage of the interaction between activity systems of health care.

The process of analysis in article III included the identification of the patients' experiences of health care. The experiences of 'being orphaned' and 'being abandoned' represented experiences that were described again and again in patients' interviews. After selecting these experiences, I searched for them and the ones that resembled them in the transcribed data. The article reports the examples of the experiences in their various organizational and social connections.

Article V involves the analysis of the expansive learning process that took place in the Change Laboratory sessions during the second phase of the intervention. The analysis began by listing the use of the new tools in patient cases. After that, the central elements of expansive learning were identified. These were resistance, the identification of the turning points, the formation of the new instrumentality, the discovery of the gaps, and the stabilization and maintenance of the expansive learning. The analysis proceeded by analyzing the contents of these elements.

In article VI, the analysis of the social interface began with the identification of disjunctions in the transcripts of the research data. After that, the disjunctions were listed as they were presented and discussed during each patient case in phase two of the intervention. Then the analysis proceeded into listing solutions for the disjunctions. Finally, the discussion concerning the organizational arrangements that might minimize the disjunctions was presented.

6 Central findings of the study

6.1 Central findings of the published articles

In this chapter, I present the central findings of the study. Table 6.1 gives an overview of the central findings of the articles in terms of the research problems, data, main concepts, and the main findings of the articles. The table also presents the relationships between the research questions of the dissertation and the research questions of the articles.

1. *The 'border zone' is fragmented by organizational and practice boundaries.* The constellation of illnesses, i.e., the object of practical activity, had an impact on how the organization of a patient's care emerged at the 'border zone' (see, for instance, the patient care map in article I, p. 60 and in article II, p. 42).²⁵ Many providers in various care locations provided the care, with the consequence of disruptions in the flow of information and the lack of an agency having the overall responsibility for the care provision. The identified boundaries of the care provision related to the division of labor and the norms or rules evolved in organizations and in professional practices. (See article I, pp. 61–64.)
2. *Collective learning can be a process of reconstructing boundaries.* Boundaries became visible when the participants voiced a problem in the patient's care provision. Collisions between the differing perspectives of the professionals led to questioning and argumentation until a shared solution emerged. Developmental and learning challenges related to the implementation of the new tools and practice. Thus, learning at the boundaries is not only a collision of different perspectives, but can also be a process of reconstructing the boundaries. (See article I, pp. 61–64.)

²⁵ The references to the articles are meant to help the reader to make connections between the summary of the central findings and the findings of the original articles.

Table 6.1. Overview of the articles and their central findings

Research Questions	Research Questions of the Articles	Data	Main Concepts	Main Findings of the Articles
What are the boundary dynamics of development, learning and change in health care for patients with multiple and chronic illnesses?	<p><i>Article I</i></p> <p>1. What kind of places are the Implementation laboratories for learning a boundary encounters?</p> <p><i>Article II</i></p> <p>1. How the boundaries between primary, secondary and tertiary care are expressed in interaction? 2. How are the boundaries between primary and secondary care expressed in interaction? 3. What kind of problems and challenges related to development and change emerge in the interaction between health care providers?</p> <p><i>Article III</i></p> <p>1. What kind of experiences of 'homelessness' and abandonment' do the patients report of their health care? 2. How do the patients explain these experiences? 3. What kind of learning challenges do the patients' experiences raise for providers?</p>	<p>Implementation Laboratory session (Tommi's case)</p> <p>Implementation Laboratory session (Mark's case) The data gathered before the laboratory session</p> <p>52 Patient interviews (26 patients)</p>	<p>Boundary encounter, 'border zone', expansive learning</p> <p>'Boundary expression', 'discursive boundary action', boundary encounter</p> <p>Patient experience, boundary effect</p>	<p>1. 'Border zone' is fragmented by organizational and practice boundaries. 2. Collective learning can be a process of reconstructing boundaries.</p> <p>3. Practitioners and patients mark boundaries in their talk. 4. Joint reflection makes possible boundary crossing in the Change Laboratory session.</p> <p>5. Patients frequently experience uncertainty and neglect in their care.</p>
2. How are the boundaries of health care activity constructed and reconstructed in social interaction within a Change Laboratory intervention?	<p><i>Article IV</i></p> <p>1. How do the boundaries appear in discussions according to cultural-historical theory? 2. How do the boundaries identified evolve during discussion?</p>	<p>Implementation Laboratory meeting (Mark's case)</p>	<p>'Landmarks' of boundaries, boundary expression' and the activity-level of boundaries</p> <p>Boundary crossing, routine</p>	<p>6. Questioning and transforming boundaries is a demanding learning challenge.</p> <p>7. Boundary crossing in tool-implementation includes dissolving, reshaping and stabilization of the prevailing routine practices.</p>
3. What are the dynamics of boundary crossing in experimentation with the new tools and new practice?	<p><i>Article V</i></p> <p>Theoretical challenges examined: 1. Organizational learning is not only the formation of collective routines; it is also tool-creation and implementation. 2. Tools evolve as they are implemented 3. Tools become powerful when they become interconnected instrumentality and constellations.</p> <p><i>Article VI</i></p> <p>1. What kinds of disjunctions emerged as a result of new socio-organizational interfaces? 2. How could these disjunctions be addressed? 3. What kinds of new organizational arrangements might minimize these kinds of disjunctions?</p>	<p>Six Change Laboratory sessions in the 2nd phase of the project</p> <p>Six Change Laboratory sessions in the 2nd phase of the project</p>	<p>Socio-organizational interface, disjunction (object)</p>	<p>8. Providers are willing and able to produce solutions to disjunctions that supersede speciality and service boundaries in inter-organizational care.</p>

3. *Practitioners and patients mark boundaries in their talk.* The linguistic means used in the marking of the boundaries included (1) the explicit terms ‘boundary,’ ‘border,’ and ‘limit’; (2) metaphors; (3) expressions referring to actor’s attributes and social relations; and (4) references to locations of care. The terms ‘boundary,’ ‘border,’ and ‘limit’ and metaphors were rarely used, but instead distinctions referring to persons, professionals, or professional groups and the naming of places of care according to their locations appeared often. Boundary expressions were linked to the multi-organizational context that was represented in the elements of an activity system. Boundary expressions referred to the division of labor, rules, and tools of inter-organizational collaboration, and to distinctions between a patient and professionals in the health care organization. (See article II, pp. 43–51.)
4. *Joint reflection makes possible boundary crossing in the Change Laboratory session.* Besides problems and challenges, joint reflection enables development and learning at the Change Laboratory session. During the session, participants were able to perceive the overall pattern of the patient’s care provision and the realization of the emergent inter-organizational object of multiple illnesses, while in normal practice each participant would focus on a single disease only. As a consequence of the emergent new object, some participants began to question the prevailing forms of collaboration between primary and specialized care. That questioning led to reflection on the object of the overall care provision and the ‘crossing over’ of the prevalent boundaries, i.e., a new division of labor between care providers emerged. The emergent temporary activity made it possible to provide care in a more sensible way for the patient in the future. (See article II, pp. 51–56.)
5. *Patients frequently experience uncertainty and neglect in their care.* The experiences of ‘being orphaned’ and ‘being abandoned’ represented experiences that patients may have in their health care. In the accounts of being a patient in the health care system, the experience of ‘being orphaned’ relates to uncertainty about the provided care. For instance, a patient felt that he himself had to take more responsibility in regard to the availability of his medical history during the examination since he usually saw a different specialist at every visit. Due to problems in the information exchange, another patient experienced ‘being cast adrift,’ while a third patient experienced her state as being in ‘crisis’ because her care and treatment varied at the different care locations. (See article III, pp. 6–8.)

The patients' feelings of 'being an auctioned pauper'²⁶ refer to ill-treatment, neglect, subordination, and even humiliation in the health care system. 'Being like an auctioned pauper' appears as submitting to one's fate and subordination to what is being given, and an 'auctioned pauper' is 'tossed around.' (See article III, pp. 8–10.) Some of the descriptions even involve social exclusions, as is demonstrated by words such as 'old,' 'pensioner,' and 'second-class citizen' when the care is not provided properly (see article III, pp. 10–13).

Gaps in the information exchange and problems in the coordination of care relationships represented the developmental and learning challenges in the multi-organizationally provided health care (see article III, p. 14).

6. *Questioning and transforming boundaries is a demanding learning challenge.* Unresolved boundaries affect the practices of health care as disruptions, questions, dilemmas, or problems that are not easy to resolve. The tensions were reported to derive from the need to re-interpret the object of health care, i.e., the care of patients with multiple illnesses. During the Change Laboratory sessions, the participants became aware of the boundaries when the patient's constellation of care was presented with the care calendar and care map. (See article IV, pp. 177–181.) The mirror also showed the obstacles and tensions in the patient's care provision as presented by multiple providers in interviews and during the patient's visits to primary or secondary care. These examples presented in the Change Laboratory meeting created a double bind between the participants' everyday practices and the constellation of care. The strained relationships between primary, secondary, and tertiary care could, however, be negotiated. The professionals' need for new rules and re-definitions of the care responsibility was recognized. (See article IV, pp. 181–183.) Two boundaries were identified in the interaction. The first boundary was the institutional and organizational boundary between the levels of care. The second boundary was created by the 'sovereignty' of medical specialties between the care of individual diseases and the integrated care of multiple diseases. (See article IV, p. 184.)
7. *Boundary crossing in tool implementation includes the dissolving, reshaping, and stabilization of the prevailing routine practices.* Article V explored the dynamics of boundary crossing in tool creation and implementation. During the process, the members of the pilot group appropriated the new tools in the care of

²⁶ A cultural representation related to the history of public assistance of the poor in agrarian Finland. This is explained further in article III.

their patients. Tool creation includes the dissolving, reshaping, and stabilization of the prevalent routine practices. The findings of article V report the process of expansive learning, including the productivity of resistance, turning points, the formation of instrumentality, the discovery of the gaps, and the outcome of the learning that materialized in the model of 'negotiated knotworking.' (See article V, pp. 348–350 and figure 1 on p. 350.)

Resistance to learning emerged as not using the care agreement tool in the intervention (see table 1 on p. 347). However, resisting 'the new' also meant assessing the usefulness of the 'new' in the practical activity (see Kindred, 1999). The practitioner's use of the care agreement in session four marks the turning point in the process of organizational learning. After the turning point, the care agreement was adopted, and the formation of instrumentality began. Instrumentality refers to the joint use of a mediating instrument in producing an object and motive of an activity. The enrichment of the new instrumentality emerged as scripting the new activity, e.g., 'negotiated knotworking.' The enrichment of the new instrumentality was also represented in the variety of the professional's own tools. Observations of the gaps in the late phase of the learning process uncovered the difficulties of implementation in the practical activity of health care organization. The model of 'negotiated knotworking' was created to stabilize and maintain development and learning at the organizational level of activity. (See article V, figure 1 on p. 350.)

8. *Providers are willing and able to produce solutions to disjunctions that supercede specialty and service boundaries in inter-organizational care.* Disjunctions at the level of information exchange emerged when providers followed the routine of sending referrals and providing feedback about the care between primary and secondary care. This type of practice broke down, however, in cases that involved extended and more complex care procedures. (See article VI, pp. 9–12.) Providers may fulfill their share of the care provision, but the locus of overall responsibility for the care provided was often left undefined, particularly when patients had multiple and parallel care episodes due to complicated diseases or symptoms (see article VI, pp. 12–14).

6.2 Answers to the research questions

6.2.1 What are the boundary dynamics of development, learning, and change in health care for patients with multiple and chronic illnesses?

The answer to the general research question of what the boundary dynamics of development, learning, and change are in health care for patients with multiple and chronic illnesses is addressed briefly at the beginning of this section, and more thoroughly in the summary of this chapter. The findings of articles I and II (see table 6.1) address the general research question.

First, the dynamics of development, learning, and change were investigated as a ‘border zone’ in each patient’s care provision. The ‘border zone’ as well as the constellation of the health care organization varies in the care practices of patients with multiple and chronic illnesses (see the first finding in table 6.1). Some characteristics of the health care organization are, however, repeated in the patients’ care provision, e.g., the ruptures in information exchange and the need to find a responsible agency for the overall care of patients with multiple illnesses. These ruptures and needs refer to developmental challenges in the care of patients with multiple and chronic illnesses.

In the articles, the health care organization was depicted in the patients’ care maps (see, for instance, the care maps in article I, p. 60 and article II, p. 42). According to the care maps, each patient seems to create his or her own health care organization. But the providers are not usually focusing on the provision outside their specialty or the level of care (see, for example, excerpt 12 in article II on p. 53). The care organization appeared to be fragmented and divided by the boundaries only to the patients (see, for instance, the excerpt in article I on p. 61).

Second, the articles depict collective learning as taking place in the intervention. Interventions create an interactive ‘border zone’ between the patients, providers, and researchers (see the second and the fourth finding in table 6.1). At the border zone, the providers can reflect a patient’s care organization through the ‘mirror.’

In the change project, the researchers created ‘mirrors’ for the providers by creating an overall view of a patient’s care provision. It was presented on the care calendars and care maps at the laboratory sessions.²⁷ Furthermore, the ‘mirror’ provided glimpses from the actual care practices as edited video clips (see article II, pp. 40–43 for a description of the data and methods of the Change Laboratories). The participants of the laboratory sessions were able to use the ‘mirror’ in

²⁷ During the second phase of the project, the participating practitioners also created care calendars and care maps (see article V).

collective problem solving that would be beyond the possibility of their day-to-day actions. For instance, the practitioners were able to see that a patient's care provision is constituted and fragmented by various objects of care (see figure 3 in article II, p. 52). Through collective problem solving, the providers can learn to create a shared object of a patient's care organization that is important in the overall care of a patient (see, for instance, the discussion in article I, pp. 61–62).

Expansive learning emerges at the Change Laboratory sessions as questioning of the prevailing boundaries between the levels of care. For instance, the flow of information and the division of labor between professionals representing different levels of care are questioned (see article I, pp. 62–64). This questioning can lead to crossing and negotiations of the prevailing boundaries between the levels of care (see article II, pp. 53–56). Hence, expansive learning can be a process of reconstructing boundaries that takes place at the 'border zone' in multi-organizational care.

Third, interaction at the 'border zone' illustrates how boundaries are expressed in the practitioners' talk (see the third finding in table 6.1). The border zone of this study is fragmented by organizational and practice boundaries. The boundaries of this study relate to the division of labor, rules, and tools in inter-organizational collaboration, and to distinctions between a patient and professionals in the health care organization. Expressing boundaries is, however, implicit, and various linguistic means are used in social interaction. Boundaries can, however, be traced in boundary expressions, which are the 'landmarks' of boundaries. Instead of being clear distinctions, the boundaries appear to be 'blurred' with tensions.

6.2.2 How do individual patients experience boundaries in their health care?

Patients with multiple and chronic illnesses frequently experience uncertainty and neglect in their health care (finding 5 in table 6.1). The findings illustrate that a new kind of care needs to be developed for patients with multiple and chronic illnesses.

Experiences of 'being orphaned' and 'being abandoned' point to the uncertainty, neglect, subordination, and even humiliations in patients' health care. The experiences reported in article III suggest that Finnish health care for patients with multiple illnesses includes uncertainties in multi-organizationally provided care. The uncertainties of care relate to gaps in the information exchange and problems in the coordination of care relationships as the following excerpt illustrates (excerpt 1 in article III, p. 7).

Patient: The thing that bothers me the most is that (...) ²⁸ the specialists keep changing almost every time [I go to the doctor] (...). They have to start from the very beginning and check through the whole pile of [patient] documents, which is huge. (...) And then I have to be alert all the time and fill in some details. (...) If there were a familiar physician of my own who would be better acquainted with [my ailments] and he could better remember the last visit and what was the trouble with me then, it would be a different thing. But it is like this. The outpatient clinic works this way. (...) *I feel so orphaned*. But I don't mean [that the physicians are bad]. All these physicians are (...) specialists (...) and of course they know their work well. (P10 March 5, 2001)

The experiences of 'feeling like an auctioned pauper' described the neglect, subordination, and even humiliation that the patients with multiple illnesses feel in their care provision as the following excerpt illustrates (excerpt 10, article III, p. 10. See also excerpt 9 in article III, p. 10).

Patient: One physician said that you are at that age that you can *take it* [your condition] with you *to the grave* so it will not be operated on (...). Well, it creates a kind of contradictory condition. (P26 December 10, 2001)

Besides the challenges in the functioning of the organization, there are also challenges in the ways these patients are treated in inter-organizationally provided care as the following excerpt illustrates (excerpt 6 in article III, p. 9. See also excerpt 7 in article III, p. 9).

Patient: Then when I got this (...) pneumonia (...) the ambulance took me to the primary care hospital. I said to them that I don't belong here. I said (...) that you should take me there [to the secondary care hospital]. And my pneumonia would have certainly been treated the right way. (...) Well, then what happened was that they did not do anything [at the hospital]. The physician said at first that I have to be taken for x-rays. Nobody took me there. (...) I was left collapsed [on the wheelchair]. I hardly was able to stand up. I was left there. (...) Well, I thought, here I am again *almost in the position of an auctioned pauper*. Just like when M. [the personal physician] moved away, then I said that I will be *the auctioned pauper*. I feel like nobody cares for me. (P15 October 12, 2000)

²⁸ Three dots in the brackets (...) mark the removed data. The language of the original excerpts is edited for this publication.

6.2.3 How are the boundaries of health care activity constructed and reconstructed in social interaction within a Change Laboratory intervention?

Questioning and transforming boundaries is a demanding learning challenge (finding 6 in table 6.1). The construction and reconstruction of boundaries are investigated in article IV. The (inter)actions of providers from different health care organizations are framed according to organizational and practice boundaries. The findings of the study display how the prevailing boundaries are defended and questioned and how attempts are made to transform them in the Change Laboratory interactions (see article IV, pp. 177–183).

The theory of expansive learning is usually applied in large-scale transformations of activity systems that last for long periods of time. Expansive learning may, however, take place in ‘miniature cycles’ lasting only a short period of time. Such miniature cycles can be regarded as potentially expansive (Engeström, 1999b, p. 385). In this study, a laboratory session represented a miniature cycle of expansive learning. The presentation of the patient’s problems created a double bind among the participants, which was then discussed in connection with the implementation of new tools in the project. The participants were oscillating between the present care provision and the opportunities provided by the laboratory session in terms of maintaining, questioning and transforming the present organizational and professional boundaries. But the questioning of the present boundaries appeared dilemmatic, and very few expressions transformed the present boundaries in the laboratory session (see table 9.1 in article IV, p. 181). Some boundaries in the care of a single patient were, however, transformed in the interaction. Therefore, the interaction may renew the boundaries of a single patient during the miniature cycle of learning, but the solutions need to expand into a larger scale expansive cycle of organizational learning. But this was not achieved in the present project as will be presented in the next sub-section.

6.2.4 What are the dynamics of boundary crossing in the experimentation with the new tools and new practice?

Boundary crossing represents a process of expansive learning, during which the pilot group re-invents the routine practices of their work. Article V details the process of boundary crossing in tool creation and implementation. Organizationally based sets of cultural rules and resources structure the behavior in the collaborative interaction in the Change Laboratory session. Rules and routines act as carriers of organizational learning and memory. Boundary crossing in tool implementation includes, therefore, the dissolving, reshaping, and stabilization of the prevailing routine practices at work (finding 7 in table 6.1).

Complexity related to the new network-type of organizations is explored in article VI. Organizational interfaces of historically derived boundaries are crossed in the Change Laboratory sessions in the experimentation with new communicative tools and practices. The experimentation creates motivation for the new work activity by discovering the gaps in inter-organizationally provided care. The findings reveal that providers are willing and able to produce solutions to disjunctions that supercede medical specialty and service boundaries in inter-organizational care (finding 8 in table 6.1). Solutions were not, however, implemented into general practice but remained encapsulated at a local level of practice.

Articles V and VI demonstrate that developing a multi-organizational health care system is a complex challenge, requiring solutions that involve multiple providers and high levels of organizational and professional involvement. The boundaries embedded in the multi-organizational field of health care represent 'silos' that cannot easily be made visible until they are crossed during tool creation and implementation. The model of 'negotiated knotworking' (see figure 1 in article V, p. 350) created during the tool creation and implementation could act as a means of transition between miniature cycles of learning and large-scale expansive learning, but it was not implemented into generalized use during the project (see table 1 in article V, p. 347 and article VI, p. 14).

6.2.5 Summary: Boundary dynamics of development, learning, and change in the multi-organizational field of health care activity

The general research question of what the boundary dynamics of development, learning and change are in health care for patients with multiple and chronic illnesses is addressed in this section on the basis of the findings that are summarized in table 6.1.

The framework of this study (figure 4.2) suggests that boundaries can act as mediators of cultural and social formations, networks, and practices. They can both prevent and enable connections between organizational activities. The framework is constituted of three activities in terms of the object. First, the practical activity of a single patients' care emerges in connection to its object of a pattern of diseases, illnesses, or symptoms of chronic illnesses. Second, the developmental activity emerges in connection to its object of a new form of collaborative work in health care organization. Third, the reflective learning activity of the participating patients and professionals emerges in connection to its object of the new collaborative work practice (see R. Engeström, manuscript). The three activities capture the hybridity of the developmental, learning, and change processes at the boundaries of health care and its practice.

The *practical activity* of single patients' care is examined during processes of change focusing on the division of labor between primary, secondary, and tertiary care in the health care organization (see chapter 1.2 of this study). Simultaneously, the care of single patients with multiple and chronic illnesses emerges on the level of day-to-day practices as fragmented by multiple boundaries. The historical analysis that was reported in chapter 3 in this study (see table 3.1 in chapter 3.1) illustrates that these boundaries have a historical origin in the Finnish health care organization and professional organization. The boundaries represent the divisions between a patient and professionals, specialties of medicine, and organizational levels of primary and secondary care. Furthermore, these boundaries have recently been consolidated as a consequence of cost-effective care and management by results in the Finnish health care system.

The developmental contradiction discussed in chapter 3.5 (see figure 3.2 in chapter 3.5) expresses the contradictions between the improved ability of medicine to provide care for chronic illnesses and the opportunities of health care organizations to be able to adopt these new improvements in single patients' care provision. One of the implications of the developmental contradiction is that the care of patients with multiple and chronic illnesses is provided by multiple providers in many locations. However, this situation is not satisfactory from the perspective of many patients, as the patients' experiences of 'being orphaned' and 'being abandoned' that were depicted in article III illustrate. These patients find this type of care provision to be uncertain and unreliable.

The developmental contradiction is also embedded in the professionals' interactions taking place in the multi-locale care. The Change Laboratory sessions conducted in the project revealed tensions that could be connected to the inter-organizational care of these patients. For instance, the exchange of information and the division of labor between providers is not secured in the health care organization that is carried in multi-locale care (see, for instance, article I, pp. 62–63).

The constellation of multi-locale care creates a 'border zone' that addresses the boundary problems spatially and temporally in the practices of the health care organization (see figure 4.2 in chapter 4.4). The problems emerge as disjunctions and overlaps in the care provision (see article VI, pp. 9–11). On the other hand, encounters at the 'border zone' could enable the change in collaborative practices between providers. In particular, the use of the new care agreement tool and related practices provides the potential for inter-organizational collaboration in practice (see article V, p. 349 or article VI, pp. 11–14).

The zone of proximal development of the Finnish health care organization presented in figure 3.3 (see chapter 3.5) can now be complemented with the empirical findings of this study. Figure 6.1 depicts the zone of proximal

development in the Finnish health care organization from the perspective of patients with multiple and chronic illnesses.

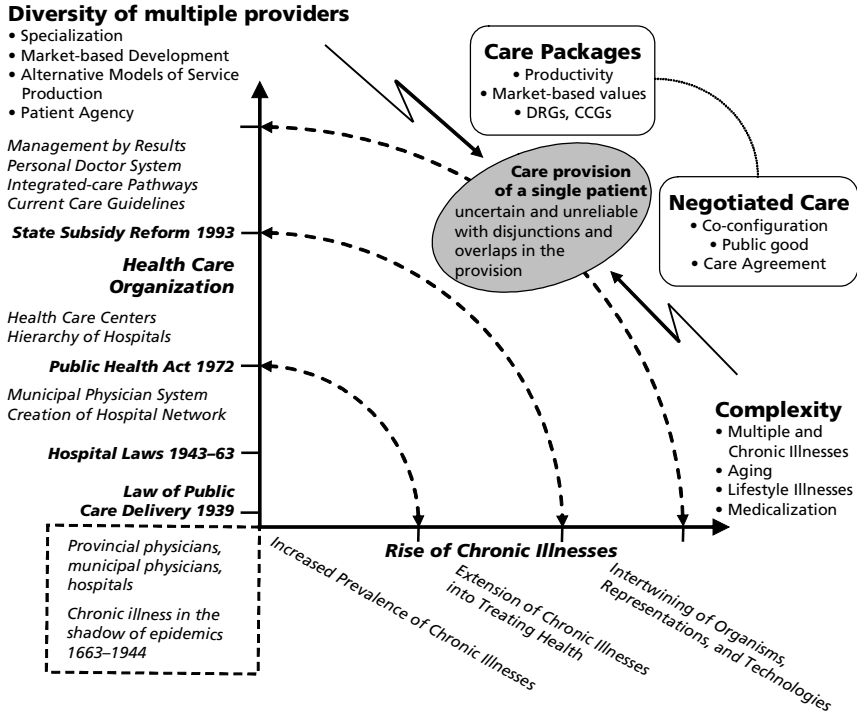


Figure 6.1 The zone of proximal development for the Finnish health care organization

Change Laboratories represent the spatial and temporal location of the expansive *learning activity* in the study. Learning is interwoven into the process of analyzing problems and the planning and testing of solutions in order to improve the medical patient care at the ‘border zone’ between activity systems (see article I, p. 64). The object of the learning activity is the work practice that is created while collectively using the new care agreement tool in single patients’ care. Change Laboratory sessions make possible the joint reflection of a common object in spite of the organizational and practice boundaries between care providers. Therefore, the Change Laboratory represents a microcosm of activity that can be more than a sum total of its single parts. According to Engeström (1987, p. 277), “A microcosm is a social test bench and a spearhead of the coming culturally more advanced form of activity.” A microcosm brings together aspects of activity and agencies that can achieve more than the sum total of their combination. Microcosms are, therefore, locations with partly unpredictable potentials

for learning and development. The construction of the overall object of health care provision in the Change Laboratories enabled expansive learning at the border zones.

During laboratory sessions, the participant professionals together with the patients learned to discover and articulate the problems in a patient's overall care (see, for instance article I, pp. 62–63). Furthermore, due to the opportunity to experiment with the new tools, the participants also were able to observe the disjunctions in that patients' care (see article VI, p. 14). Yet, the patients and the professionals also learned to observe the disjunctions before the Change Laboratory sessions when they prepared their cases for the sessions (see, for instance, excerpt 5 in article III, p. 8 and excerpt 2 in article VI, p. 10). And what is particularly important is that the pilot group members created new care practices while learning to use the new care agreement tool and reflecting on its use. For instance, the providers arranged a care negotiation with the patients and the providers involved in the patient's care (see article V, p. 349; see also article VI, p. 13).

Learning the new practice requires a long process of experimenting with the new tools (see, for instance, the process of learning in article V). The process of learning does not, however, emerge as a linear process of learning but as a cyclic process involving returns to earlier contradictions and double binds (see article VI, pp. 11–14). Besides the temporally proceeding learning process, Change Laboratories also depict the scene of the learning activity in action at the 'border zone' between activity systems. The learning activity emerges as collisions of multiple perspectives representing the different origins and object/motives of activity in primary and specialized health care (see, for instance, article I, p. 63).

The evolving boundaries represent the miniature cycle of the expansive learning process in the laboratory session. Miniature cycles of expansive learning can be potentially expansive if they are successfully integrated into the learning processes on the level of organization (Engeström, 1999b, p. 385). In this study, the boundaries of single patients were reconstructed during the miniature cycle of learning, but the solutions were not implemented into general use in the health care organizations. Managing directors of primary and tertiary care signed an agreement to implement the care agreement tools and related practices in both organizations. However, despite the evidence provided by the miniature cycle of learning at the project, the new tool and the new practice were not adopted into general use (see article VI, p.14). The study showed, however, that it is possible to involve clinical providers to collaborate across boundaries in information and care responsibility (article VI).

Developmental activities emerge as intertwined with the learning activities and are sometimes difficult to distinguish from each other. The development activity displays the processes of transitions in the zone of proximal development (see

figure 3.3), while the learning activity explores aspects of learning at the ‘border zone’ (figure 4.2).

The Change Laboratory uncovered the developmental challenges related to the fragmentation of the prevalent health care for the patients with multiple illnesses. For instance, the patients suffering from multiple and chronic illnesses consider it important to have someone who takes the overall responsibility for their care instead of many providers (see excerpt in article I, p. 61). During the Change Laboratory sessions, the providers also began to see the effects of the care provided by multiple providers in various locations of care. For instance, providers representing single specialties tended to focus on single ailments or symptoms with the risk of losing sight of the overall provision (excerpt 12 in article II, p. 53). During the development process it also became obvious that patients may have difficulties in making distinctions between their symptoms. This might have an influence on seeking an appropriate location of care for their symptoms (turn 100 in article IV, p. 179). The findings reported in article III confirm these results. These developmental challenges were also presented in the examples of patients’ experiences of ‘homelessness’ and ‘abandonment’ in article III.

The new tools (the care calendar, care map, and care agreement) were experimented with as solutions for the double bind that emerged in the laboratory sessions (see article V). The new tool-object exploration enabled tool creation and the re-construction of the new object/motive, for instance, through addressing disjunctions in the inter-organizationally provided care (see article VI). Experimentation with the new tools was not easy because most members of the pilot group resisted the new tools (see table 1 in article V, p. 347). Besides open resistance (see excerpt 1 in article V, p. 348), the agreement tools were also rejected ‘silently’ (see article V, p. 348). Table 1 in article V shows that not all the new tools were adopted at the beginning of the experimentation. Later in the intervention process, a model for negotiated knotworking was created in order to support the sustainability and maintenance of expansive learning and development in primary and specialized care (see figure 1 in article V, p. 350). However, the model was not taken into general use, as mentioned before.

The developmental process involves the dissolving and reshaping of the boundaries of the practical activity in this study (see article II, pp. 51–56). However, changing the boundaries is not easy in health care organization. The present boundaries are not easily noticed in the interaction because they are deeply embedded in regular practices, as is also observed in other studies (see Phillips, Lawrence & Hardy, 2000). Organizationally based sets of cultural rules and resources structured the behavior of collaborative interaction in the laboratory session (see article II, pp. 43–51). During the experimentation process, the boundaries of the organizational and professional communities, the division of labor, and the rules

began to be questioned (see article I, pp. 62–63 and article II, pp. 53–56). The passage in article II shows how difficult it is to have negotiations over disciplinary and organizational boundaries and how the solutions created may only remain local and temporary. Article IV illustrates that boundaries also evolve during encounters between professionals representing different organizations (see article IV, pp. 181–183), while unresolved boundaries still affect the practices of health care as disruptions, questions, dilemmas, and problems (see article IV, pp. 184–185).

In Finland, as in many other countries, chronic and complex disease provision requires the creation of organizational structures and alternative organizational arrangements that ‘cross’ specialty and service boundaries. Although the aim of securing the care for patients with multiple and chronic illnesses is shared by the practitioners representing different organizational units and levels, it is not easy to find solutions that ‘cross’ the inter-organizational boundaries (see article VI, pp. 11–14).

7 Contributions and limitations of the study

This chapter presents the contributions and the limitations of the study. First I will bring up the contributions to studies on development, learning, and change. After that, I will discuss the limitations of the study and the research process. Finally, I will also discuss the utility and the ethical dimension of the study.

7.1 Contributions to studies of development, learning, and change

7.1.1 Contributions to the development of health care for multiple and chronic illnesses in Finland

This study has investigated the health care of multiple and chronic illnesses. The need to develop health care is urgent because of the rising costs of health services and the requirements for more effective and qualified health services. Chronic illnesses are also becoming more common due to the aging of the population and improvements in acute care in Finland as well as in many other countries. Apart from the contributions of the intervention project, this study provides further knowledge about the development of health care for these patients in Finland.

The development of the health care organization is currently challenged by a central contradiction that becomes visible in the health care of patients with multiple and chronic illnesses as were discussed before (see section 6.2.5). Medical technology and professional practices produce advanced expertise and treatments at an accelerating speed, bringing about complex interdependencies between organisms, representations, and technologies. Furthermore, these developments have an effect on the aging of the population, the increase of lifestyle illnesses, and medicalization. People can live longer with more advanced medications and treatments. On the other hand, specialization, market-based development, alternative models of service production, and increased patient agency bring about the

diversification of multiple providers. As was reported in the findings of this study, cooperation and communication between providers does not run smoothly in multi-organizational health care.

This study identified two alternative models for the development of health care in Finland (see figure 3.3 in chapter 3.5). The *care package model* is based on productivity and process models adopted from engineering, market values, and diagnosis-related groups (DRGs). It focuses on single illnesses and single visits in the provision of health services. *The model of negotiated care* is based on co-configuration, the public good, and care agreements. It focuses on providing coherence of care to a pattern consisting of multiple illnesses. The negotiated care model is based on social innovation. The patients cannot, however, make a choice between these models of care. Decision makers seem to favor the care package model in many municipalities and in hospital care, while the model of negotiated care hardly exists in health care organization. However, the negotiated care model could be used beside other models for patients with similar needs for services as the ones investigated in this study.

The empirical findings reported in section 6 give examples of situations in which the model of negotiated care may be useful. For instance, the disjunctions and overlaps in the care of patients with multiple and chronic illnesses can be discovered and addressed through negotiated care. However, despite the agreement signed by the health care management of the involved organizations to implement the care agreement tools and negotiated practice, the tools and the new practice were not adapted for practical use. The innovative solutions of local learning involving boundary crossing did not diffuse into practice on the basis of management decision making. On the other hand, the connection between the middle management and the pilot group developing the new tools and the practice was too weak. Middle management, as well as other management levels, was kept informed during the project, but perhaps a more effective process of negotiation or other engagement would have been necessary. Hence, there is a need to develop co-operation between the management and the professionals working on the shop floor.

The difficulties of implementing the social innovations of this project resemble the difficulties of the diffusion of innovations in other Finnish health care projects. For instance, the national project for developing the regional electronic communication system in social services and health care did not succeed in achieving its intended outcomes (Ohtonen, 2003). Similar observations have also been made in other countries. Single adoption decisions do not support the diffusion of innovations in health care organization, but a more prolonged and negotiated process is needed (Fitzgerald, Ferlie, Wood & Hawkins, 2002, p. 1441). Fitzgerald and her colleagues (2002) found out that the diffusion of innovation is influenced by the interplay of multiple and complex factors in health care projects. In particular,

the evidence supporting new innovations is debated, and competing bodies of evidence with high levels of ambiguity are involved (Fitzgerald & al., 2002, p. 1444). Furthermore, the intraprofessional boundaries between professional and expert groups and interorganizational boundaries can inhibit the diffusion of innovation (Fitzgerald & al., 2002, p. 1441).

While new information systems have technically improved the information exchange between providers, an agency with overall responsibility is still missing in the care of multiple and chronic illnesses. The follow-up interviews of the project that are not reported in this study show that the consequences of this shortage have not disappeared in the health care organization. Some patients still feel like they are 'being orphaned' and 'being abandoned' while seriously ill and seeking care. The adoption of innovations is an active process requiring interaction. In future projects, it will be important to develop further processes of implementation and their assessment in health care organization and also to acknowledge the knowledge of patients related to the organization of health care.

The patients' knowledge of health care organization is an undervalued area of research (Williams & Calnan, 1996; Hydén, 1997; Williams, Coyle & Healy, 1998; Hydén & Mishler, 1999; Edwards, Staniszweska & Crichton, 2004; Frankel & Treger Hourican 2004). Yanow (2004) theorizes about the kinds of knowing that represent the 'local knowledge' emerging at organizational peripheries, which is often considered marginal in comparison to 'objectified' universal knowledge. However, as Yanow reminds us, and as also adopted in this study, this kind of local knowledge is needed as an essential part of a change process. In this study, the patients suffering from multiple and chronic illnesses reported on experiences of uncertainty and unreliability in relation to their care. Activity theory provided methods for studying the complexities of care involved in the patients' experiences of health care. The negative experiences of the patients were utilized in the process of developing the care.

7.1.2 Contributions to boundary studies of organizational development, learning, and change

Boundaries have become a center of interest in current studies of organization and work. Changes in global markets and forms of production have created the need to investigate organizational boundaries as complex, shifting, and socially constructed phenomena (Hernes & Paulsen, 2003). In this study, boundaries were investigated in relation to development, learning, and change. The findings of this study show (e.g., article II, pp. 43–44) that boundaries are usually expressed indirectly in interaction. The indirect expressions often refer to social relations and locations of care, thus, hinting implicitly at the existence of boundaries.

I studied boundaries simultaneously as outcomes of social change on the ‘macro’ level of activity and in the boundary processes of development and learning on the ‘micro’ level of ‘boundaries-in-action’ and interaction. The boundaries between a patient and professionals, specialties of medicine, and the organizational levels of primary and secondary care cause disjunctions and overlaps in the health care organization. Boundaries were studied in the interaction between providers representing different organizations of care as embedded in the context of the interaction. Boundaries were studied in “talking work” (Iedema & Scheeres 2003) in which participants not only engage in the interaction that describes the boundaries but also enable the re-constitution of boundaries. In that sense, this study is close to studies of discourse that focus on “how ‘objectivity’ is construed, achieved and contested” in its historically derived connection (Iedema & Wodak 1999, pp. 12–13).

The institutional and organizational contexts of the discourse are re-created during discourses (Hardy & Phillips, 1998; Phillips, Lawrence & Hardy, 2000; Phillips, Lawrence & Hardy, 2004). This study differs, however, from the abovementioned studies of discourse in that it focuses on the intertwining of the discourse and action in the creation of new structures. For instance, I followed the patterns of actions of the medical professionals while they were involved in a new kind of collaboration in multi-organizational care (see for instance article V, p. 349). Phillips and his colleagues suggest that instead of studying structures in terms of patterns of actions, structures can be examined through texts that describe and communicate those actions (Phillips, Lawrence & Hardy, 2004, p. 635).

The developmental process reported in this study involved the dissolving and reshaping of the organizational and practice boundaries. The examined project illustrated that it is possible to interweave the fragmented relationships between providers through the creation of new tools and related collaborative practices in expansive learning. However, in these processes, boundaries restricted the actions and interactions of the patients and professionals while simultaneously enabling a new kind of collaborative activity to emerge in discursive social practices and material realities. The new practice, the ‘negotiated knotworking,’ developed during boundary crossing in the multi-organizational collaboration between providers. But these developments did not become sustainable in the organization. They became encapsulated in the practices taking place in the intervention. The problems of diffusion may relate to questions of power. The participants did not perhaps possess enough power to create sustainable change.

Power plays an important role in the negotiations that constitute the collaborative process in a multi-organizational context (Phillips, Lawrence & Hardy, 2000, p. 32). “Actors must hold subject positions that warrant sufficient voice, as recognized by others, otherwise the impact of their activities or statements will be

minimized” (Hardy, Palmer & Phillips, 2000, p. 1245.) The issues of power were, however, only touched in this study (see article III, pp. 9–10). The issues of power in collaborative activity seem to be an important topic for activity theoretically oriented research in the future. In particular, the processes of change engaging both the managerial level and the level of the practitioners need to be studied. In this study, the management of the health care organizations participated as a steering committee in the intervention. In future studies, a more involved engagement of management is needed.

Boundaries are a potential context for studying the development of new organizational forms in multi-organizational collaboration, as this study has illustrated. Processes that take place at the boundaries are not easy to carry out. The actions of the practitioners are restricted by the rules and divisions of labor created in the past activity, as the findings of this study illustrate. However, multi-organizational “collaboration involves the negotiation of roles and responsibilities in a context where no legitimate authority sufficient to manage the situations is recognized” (Phillips, Lawrence & Hardy, 2000, p. 25). This makes multi-organizational collaboration a fascinating future area of study.

7.1.3 The significance of an object in the construction and reconstruction of boundaries

The collective object of activity is considered to be an essential aspect of development in human activity. The object includes both culturally available and constructed social and material aspects of essence that are meaningful to members of a community (Engeström, 1987). In human activity, an object of activity emerges as embedded in economic and social relationships (Miettinen, 2005, p. 58). For instance, in health care an object of activity is outlined according to the division of labor between levels of care and medical specialty. As far as a patient is concerned, a patient transforms his or her experiences of ailments into a meaningful pattern of illnesses and symptoms by using culturally accumulated conceptualizations (Engeström, 1990, p. 109).

I described the current challenges related to the conceptualization of the object of multiple and chronic illnesses based on the literature review in chapter 2 (see figure 2.1). In the review, I explored (1) the perspective of medical science, (2) the studies focusing on the life-world of human beings with chronic illnesses, (3) the field of managed care and disease management, and finally (4) the co-emergence of previous and new perspectives in the care delivery of chronic illnesses. Multiple and chronic illnesses as well as their provision was considered to have become complex (Goldberg, 1996; Davis & al., 2000; Wagner, 2001; Wagner & Groves, 2002; Wilson & Holt, 2001).

The challenges depicted in the literature of providing care for chronic illnesses (see the complex zone in figure 2.1) were explored and discussed further in this study as developmental challenges embedded in the health care organization and its object of activity. I also traced the formation of the object in the history of Finnish health care organization (Chapter 3).

According to the findings of this study, the object of multiple and chronic illnesses did not exist as a coherent object in practice since the care provision is fragmented by various providers who represent many professional fields of expertise and practice in multiple locations of health care. Single providers did not necessarily pay attention to the incoherence and fragmentation of the object since they are only concerned about the aspects of the object included in their own responsibilities and tasks. Correspondingly, Saaren-Seppälä (2004, p. 112) observed that health care professionals split up illnesses and symptoms into parts according to the division of labor in children's health care. According to Freidson (1988, p. 182 cited in Saaren-Seppälä, 2004, p. 112), it is a common practice to have a responsibility of one's own without intervening in that of others unless it has an influence on one's own responsibility.

On the other hand, the object was experienced as the overall pattern of multiple and chronic illnesses by the patients and also by some providers. Particularly those providers participating in the Change Laboratory project began to focus on the overall of object of care for chronic illnesses in which the constellation of illnesses and their care was connected. In normal practice, outside the change project, the connections between the fragmented parts of the object included transitions from one level of care to another with a formal referral or a care feedback note. However, the care provision was often limited to a single unit with no knowledge of the treatments provided elsewhere, despite the fact that the provision was connected in terms of the illnesses.

The fragmented but experientially integrated object of multiple and chronic illnesses acted as a driver of change in the development and learning at the Change Laboratory sessions. It raised tensions, disruptions, and disjunctions in terms of the care practices that were observed as developmental challenges of the current health care activity. The challenges were explored as part of the hybrid activity that took place at the Change Laboratory.

The hybrid activity consists of practical activity, learning activity, and developmental activity. The co-presence of multiple activities complicated the object of activity. While the object of the practical activity is the pattern of multiple and chronic illnesses, the object of multiple and chronic illnesses is extended to include the emergent new collaborative form of work in the developmental activity. Furthermore, in the learning activity, the object is the entire work practice that is included in the use of the new care agreement tool (see chapter 4 and especially

figure 4.2). One of the contributions of this study was, however, to bring together the fragmented aspects of the object with a new sense and meaning of the collaborative activity that extended over the prevailing organizational, professional, and practice boundaries. The significance of an object is, therefore, related to creating a new sense and meaning of an activity in the construction and reconstruction of boundaries. Future studies of boundaries need to acknowledge the object of an activity in the construction and reconstruction of boundaries.

7.1.4 The boundary dynamics of development, learning, and change

The complexity science approach in health care suggests that complexity could be mastered through experimentation, autonomy, and work at the edge of knowledge experience (Plsek & Greenhalg, 2001, p. 627). Developmental and learning approaches involving reflection, such as Schön's (1983) reflective practitioner and Kolb's (1984) experiential learning model, are recommended as solutions for complexity (Plsek & Greenhalg, 2001, p. 627). Both models of learning are established approaches in the tradition of adult education theory. Schön's model represents, however, an adaptive model of learning in which the reflection of basic assumptions and values may only lead to repeating the prevailing organizational reality, including its problems and failures. The model of experiential learning (Kolb, 1984) is based on a historically specific and unilateral mode of experience (a feedback session in T-group training) that is generalized into a general model of learning (Miettinen, 2000).

In this study, the contribution of cultural-historical activity theory is to provide a theoretically based approach (Engeström, 1987) for studying the development, learning, and change emerging in the complex zone of health care organization. Activity theory suggests that, besides reflection, new tools, rules, and division of labor are also required in the development, learning, and change of the care provision for multiple and chronic illnesses.

The boundaries in the multi-organizational field of health care organization created a focus on development, learning, and change that was called the 'border zone' (see chapter 4.4). 'Border zones' became the locus of hybridized behavior, conflicts, and contradiction where the reconfiguration of social patterns of actions took place. Besides the horizontal learning between representatives of the multiple organizations, the movement between the prevailing activity and the new activity, which emerges as peripheral to the central activity, are also explored at the border zones.

Lotman (1990, p. 125) describes a semiotic space of culture, a semiosphere, which is characterized by the dynamics between the center of the semiosphere and its periphery. The center of the culture expresses the most stabilized forms

of culture, while the periphery represents the heterogeneity of the culture. The periphery emerges as intertwined with the boundary of the semiosphere, which is considered to be a mechanism for generating new forms of culture (Lotman, 1990, p. 131).

In this study, the boundaries represented the 'outer limits' of the prevailing health care activity. The aspects of cultural center and cultural periphery illustrate the degree of certainty and agreement in terms of the certainty-agreement diagram as depicted by Plsek and Greenhalg (2001). The degree of certainty and agreement is high in an activity when it represents its cultural center and low in an activity when it represents its periphery. Close relations to the cultural center involve stable boundaries, while a distance from the cultural center involves blurring of the boundaries. The complexity of the health care is related to the degree of the certainty and agreement in the multi-organizational field of activity in the health care organization.

Instead of translations, as described in Lotman's model, new forms of activity develop through expansive learning at the boundaries and due to the boundaries in present health care activity. The zone of proximal development presented in chapter three (see figure 3.3 and 6.1) displayed the area of change that can be achieved during expansive learning and development (Vygotsky, 1978; Engeström, 1987, p. 174). According to the findings of this study, the border zone involves potentials of development, learning, and change related to the object of multiple and chronic illnesses and its socio-material connections in the health care organization. The developmental and learning processes depend, however, on practitioners' ability to create an agency that expands the level of actions into a collective activity and practice in order to be able to create sustainable change on the level of organization. Processes related to aggregates that extend the level of action are an important topic of future research in which the processes of development, learning, and change reported in this study represent the early stages of study.

7.2 Reflections on the limitations of the study

In this section, I will evaluate the limitations of the study, the research process, and the research findings in terms of their reliability, validity, and generalizability. I will also discuss the utility and the ethical dimension of the study.

The reliability of the research findings refers to the repeatability and, therefore, to a degree of consistency of the findings (Davies 1999, p. 85). The consistency of the findings can be secured through crosschecking the information and interpretations (Davies 1999, p. 86). In this study, the consistency of the findings was

either secured through several interviews with the same patients, several interviews with different professionals, patient files, or through the discussion of the findings at the Change Laboratory meetings. With this method, consistency was secured for 25 patients.

Davies (1999, p. 86) also suggests that the intersubjective agreement of the research findings represents the reliability of the study. One way to secure the intersubjective agreement of the research findings is the degree of overlap with other similar studies. For instance, Engeström (2000a), Engeström (2001), R. Engeström (2003), and Saaren-Seppälä (2004) study the development of multi-organizational health care. These studies report similar uncertainties of care as were seen in this study, such as an uncoordinated character of care involving overlaps and gaps in inter-organizational care, and problems in the information exchange between providers among pediatric as well as adult patients. However, this study clarifies the patients' perspectives and the emotional experiences of care attached to uncertainties of care, which were not researched in those studies. Engeström & al. (1995), Engeström & al. (1999), and Engeström (2003) investigate expansive learning in boundary crossing. However, this study also illustrates the historical origin of the boundaries. R. Engeström (2003) studied the multi-voicedness of experiencing in health care. Besides the active interpretation of symptoms, the experiencing also includes that of being a patient in health care. In this study, the focus is on the experiences of being a patient with multiple illnesses in health care.

The *validity* of the research findings refers to the truth or correctness of the findings (Davies, 1999, p. 85; Silverman, 1993, p. 149). Altheide and Johnson (1998) emphasize the accuracy or the 'truthfulness' of the research findings. The truth of the research findings is always interpretative as social life itself is interpretative. However, most qualitative researchers still agree that "[a]n account is valid or true if it represents accurately those features of the phenomena that it is intended to describe, explain and theorize" (Altheide & Johnson, 2000, p. 288/Hammersley, 1992, p. 69). The goals of the research and the audience that the study is intended for need to be identified in assessing the validity of a qualitative study. Furthermore, Altheide and Johnson (1998, p.288) maintain that an accurate description of knowledge and knowledge claims involves reflection on "the process, assumptions, location, history, and context of knowing and the knower."

The validity of the 'ethnographic truth' is often gained in the immersion in the fieldwork. In this study, the accuracy of the findings is secured through a description of the research context and setting and the explication of the theoretical framework, methodology, and method. The field did not exist 'as such' but was collaboratively constructed by the patients, providers, and the researchers. The 'field' became visible in day-to-day practices of care that were repeated over and

over again in tracing the pattern of a single patient's care provision. The Change Laboratory method enabled the construction of the 'field,' and the sessions acted as locations for the discursive construction of the field. The explicit goal of the study was to gain insight into the problems of health care for patients with multiple illnesses in order to develop that care. The relationships between the patients and the researcher became intimate during the research process, allowing the researcher to gain insight into the patients' personal experiences of illness. My loyalties and commitment were to discover the patients' perspective, but not to undermine the perspectives of the professionals and the health care management. The position of the researcher became one who spans the boundary between the patients' world of illness and the worlds of the professionals, the management of the health care organization, and other researchers, as described in the following section. The participants also represent the groups that make up the audience of this study.

The generalizability of the study defines the broader significance of the study (Davies, 1999, p. 86). The generalizability of the research findings refers to the representativeness of a sample or a case to a larger population (Silverman 1993, p. 160). However, in a recent article, Gobo (2004, p. 453) maintains that "(i)n qualitative research, generalizability concerns general structures rather than single social practices, which are only an example of this structure." Therefore, a researcher makes generalizations on structural aspects that can be observed in other cases or events of the same kind or class, and the recurrence of the case or the event is not needed to make the generalization (Gobo, 2004, p. 453). In this study, the generalization is based on a historical explanation. The selection of the patients for the study was carried out on the basis of the historically relevant features of the present health care system, in which patients are delivered care in the network of health care organizations through critical care pathways. The patients with multiple illnesses represent patients whose overall care is not carried properly in this system that provides their care via multiple, separately planned care pathways.

The generalizability of the ethnographic research can also be assessed in terms of empirical generalization (Davies, 1999, p. 90). Empirical generalization refers to the extension of the research findings to other studies. In this study, the empirical generalization to other studies is realized through other research projects. The project 'New forms of expansive learning at work: The landscape of co-configuration' of the Finnish Academy 'Life as Learning' research program (<http://www.aka.fi/learn>) gives an example of both kinds of generalizations. The empirical extensions of this study are the sub-project of the project 'New forms of expansive learning' that was carried out in another city than this study to improve the care of patients with multiple medical, social, or psychological needs. The project adopted the tools that were developed in this study to the ongoing collaboration within

the network of patients and various health care professionals. The tools became further developed during the project. For instance, the pattern of a patient's care that was explored with the care calendar and care map tool was called a contextual analysis. The object of research was also extended to patients with social and psychological needs.

The practical *utility* of a study is usually discussed in ethnographic case studies that are connected to the development of their research objects (Chambers, 2000). The criteria of such an evaluation include the accessibility of the knowledge to those involved, the relevance to the goals of those involved, the responsiveness to different claims upon the significance of a course of action, credibility in terms of standards of evidence and proof, and the addressing of matters of prospect and judgment (Chambers, 2000, pp. 863–864).

The accessibility of the knowledge of this study was secured through reporting (Engeström & al., 2001) and through arranging a large seminar at the end of the project in spring 2002. Professionals from primary and specialized care, the political decision makers involved, and representatives of health care management were invited. The members of the research group and pilot group presented the outcomes of the intervention.

“Research is relevant when it either adds to knowledge or increases the confidence with which existing knowledge is regarded” (Mays & Pope, 2006, p. 52). One of the contributions of this study was to bring up knowledge about the overall care of the patients that was otherwise unconnected but needed to be connected in order to be effective. Therefore, the relevance of the goals of the health care organizations and single patients were met, at least to a certain degree. The goals of the health care organization at the time related to increasing the effectiveness of health services and improving co-operation between primary and specialized care. Single patients expressed needs for more coherent health services, but the needs of patients in general were not surveyed. The study responded mainly to the significance of care provision from the perspective of single patients. However, the professional perspectives were also met with a response when they were brought up in the discussion at the Change Laboratories.

The criterion of credibility was evaluated in terms of the criteria set for qualitative studies. Qualitative research is based on systematic observations of events and people to find out about behaviors and interaction in natural settings (Mays & Pope, 1995). Qualitative research is often criticized for lacking scientific rigor. However, the nature of knowledge can be assessed in qualitative research by ensuring that the research is carried out systematically using transparent methods of data collection, interpretation, and communication (Mays & Pope, 2006). Chapter 5 describes the methodology and methods of the study, which can, therefore, be evaluated by reading that chapter.

The matters of prospect and judgment related to the understanding of the stakeholders' and clients' future interests were explored in this study, as reported in the articles and in the next section. The future needs are mainly concerned with finding solutions to the present problems of multi-organizational care. The health care provision was investigated as it emerges in day-to-day situations of care, which were then discussed among those involved.

The ethical dimension of observational research always involves intrusion into people's lives. In particular, studies seeking to use the research findings to effect social and institutional change may harm those who are studied (Angrosino & Mayas de Pérez, 2000). In this study, the ethical issues were secured by giving information about the study to the patients and providers, and by asking their permission to carry out the study. The permission obtained was documented on an official form created in the project. The project also fulfilled the other aspects of the research ethics required by Finnish Law and the participating organizations. Moreover, in day-to-day situations of respecting the choices of the research subjects, i.e., patients and providers followed normal ethical practices and used mutual respect. The following section attempts to clarify the ethical dimension in the research practice.

7.3 The researcher's engagement and participation in the field

The researcher's engagement in the field as a personal experience has not been discussed until recently in activity theoretical studies (e.g., Hasu, 2005; Saari, 2003). However, fieldwork is about experiences that we have about the research setting and the people participating in the research (Coffey 1999, p. 158). Personal ties to the research subject and to the 'field' highlight the emotional engagement of the researchers in the fieldwork. The researcher participation becomes part of the 'field,' and consequently, part of the ethnography (Coffey 1999). Yet, Coffey (1999, p. 2) maintains that little systematic attention is paid to the emotional and identity work that frame the fieldwork experience. Alvesson and Sköldböck (2000, pp. 22–27) criticize data-oriented methods of providing "shadowy analysis" in studies involving strong emotions, such as the fear of death. However, according to Alvesson and Sköldböck, these unreflected frames of reference implicitly influence the processing of the data.

The research focus of this study concerns severe and chronic illnesses. There is no doubt about the feelings and emotions that I encountered during the research process. Nevertheless, including the researcher's reflections on his or her involvement with the field in ethnographies is not easy. I have access to my own experiences of fieldwork through the artwork I did during the change project.

The artwork, i.e., some oil paintings, was part of my personal life and hobby, and unfortunately not intentionally connected to the fieldwork in the change project. The artwork represents my experiences in the field that I did not consider appropriate or important to reflect on during the fieldwork. Perhaps I even thought that such experiences do not represent valid knowledge. However, I suggest that emotional engagement with the research subject is an important part of research work. Davies (1999, p. 179) warns about self-indulgence and narcissistic revelations from the ethnographer. The reflections included in this study are not intended to be revelations about the researcher's personality but are brought into the discussion since these experiences are part of the constitution of the research subject.

Doing fieldwork with patients having multiple illnesses was rewarding, but on the other hand it was sad. It was rewarding because I made very good contact with some of the patients and learned a lot about the world of the 'sick' from the patients and the very skillful practitioners. It was sad because some of the patients were very ill. It happened that some of them died during the research project. However, I could not show my sadness, not even to myself. Documentation of my feelings towards the patients in the research data is limited. There are almost no examples in my field diary. It seems that I have been unable to document the feelings anywhere else than in my paintings.

In figure 7.1, I try to capture the moment of pain, or even of angst, related to illness and to the sick body as I imagined it. It is a spontaneous moment, almost a dreamlike experience, but still a depiction of contemplation in time and space. The picture depicts a critical moment of understanding something that I have closely followed but not quite experienced myself. Therefore, the painting engages the unknown danger and insecurity related to illness that I myself imagined in my fieldwork.

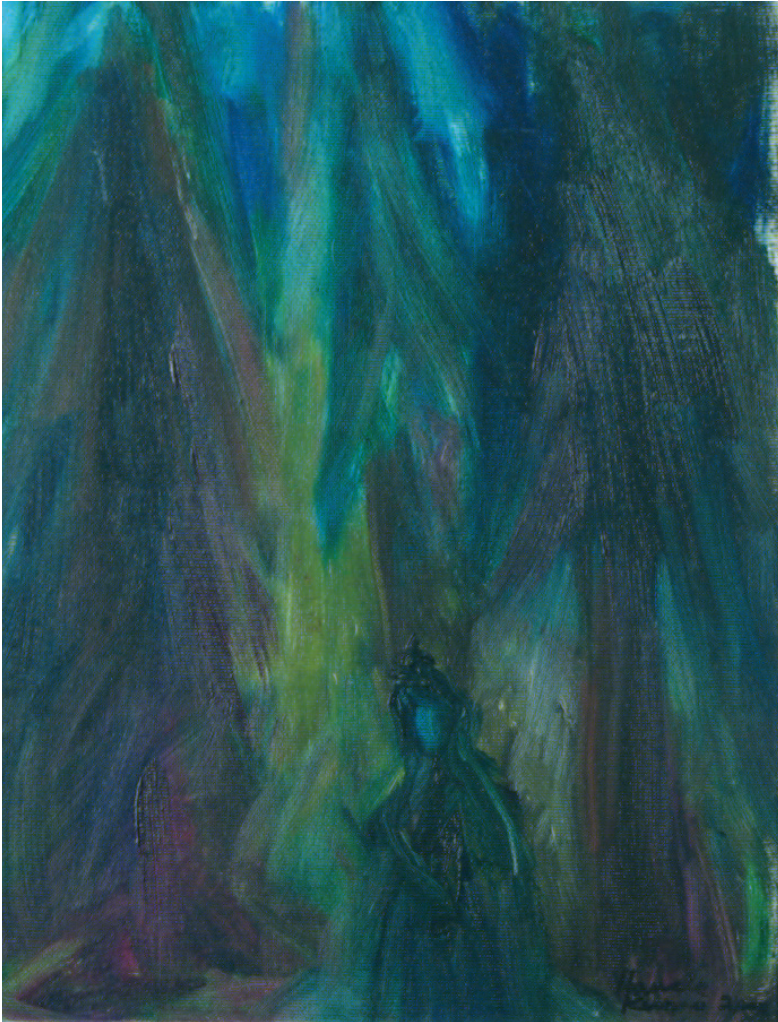


Figure 7.1 "Cry in the woods"

The painting includes the context of grieving that is typical in Finnish culture. One is not to moan or sob openly but to go to the forest and "cry to the trees of the forest," as it is phrased in an old folksong. However, the experience is meaningful to my research work. As Nussbaum (2001, p.1) insightfully maintains, "emotions shape the landscape of our mental and social lives." Nussbaum considers emotions as "suffused with intelligence and discernment." Making a reference to Proust, who calls emotions "geological upheavals of thought," Nussbaum says:

“If emotions are suffused with intelligence and discernment, and if they contain in themselves an awareness of value or importance, they cannot, for example, easily be sidelined in accounts of ethical judgments, as so often they have been in the history of philosophy.”

The emotional attachment outlined in the painting depicts the compassion I felt towards the patients. It is neither pity nor sympathy, but it could be called empathy. During an early stage of the fieldwork I realized that the patients did not want to be pitied. Feelings of empathy seemed appropriate. Nussbaum (2001, pp. 301–302) in particular highlights the distinction between empathy and compassion. For her, compassion is “a painful emotion occasioned by the awareness of another person’s undeserved misfortune,” whereas empathy designates an “imaginative reconstruction of another person’s experience, without any particular evaluation of that experience.”

In article III, the patients report their experiences of abandonment and homelessness that occurred in the findings as metaphorical representations of “being orphaned” and the life of an “auctioned pauper.” Although these experiences reflect the patients’ experience of “being a patient” in the health care organization, they cannot be separated from their experiences of illness. Both types of experience act, however, as a base for my experience of empathy towards the patients. During the research process, I began to feel deep respect towards these patients because they sincerely wanted to share their experiences with us in order to improve the health care organization in Finland.

Figure 7.2 captures the feeling of an outsider that I also experienced during the fieldwork. The painting also captures the moment that I began to see myself as an insider in a co-constitutive relationship with the patients and professionals involved with the project. The picture is a reproduction of a vivid dream I had just after New Year’s Eve, 2002. The dream felt liberating. It seemed as if I had reached a point in the fieldwork that I needed to ‘freeze’ myself in order to catch the experiences of the others. The color of the background, although warning of danger, also appears full of vitality.



Figure 7.2 "Outsider"

Fieldworkers have traditionally been considered outsiders of the group that they are studying, and fieldwork has meant traveling away from the researcher's home culture (Van Maanen 1988, pp. 2–3). Correspondingly, the process of fieldwork has meant becoming immersed in the field, i.e., becoming an insider and a participant (e.g., Davies 1999, pp. 4–5). However, recent discussions in ethnography question this presupposed taken-for-granted position between the fieldworker and the field (Amit, 2000). The eyewitnessing of the field emerges in more delicate outsider and insider positions and shifts that do not necessarily take place in distant places.

This study took place in a multi-organizational setting with shifting relationships and contexts, in which the researcher remained an outsider. In studies involving change and intervention such as this one, being an outsider is also an inevitable position since intervening involves stepping in, or interfering in any affair, so as to affect its course or outcome. Thus, an intervener is someone who comes from the outside. However, the close involvement with the private lives of the patients created an intimacy and interaction with the patients that involved the position of being an insider. As an insider, I became immersed with knowledge concerning the care of these patients. The fieldwork here can, therefore, be

characterized as a temporary field with intense relationships that include constant shifting between the positions of outsider and insider.

During the fieldwork it was not possible to establish uninterrupted relationships with the participants of the study. There were a few exceptions, however. Some patients stayed in contact with me after their case had been discussed and reflected on at the change project. Some professionals involved in several patient cases also became more steady relationships. Moreover, during the second year of the fieldwork, I cooperated with some professional members of the project when they were experimenting with new ways of care practice with their own patients. Some of these professionals, medical doctors, became closer contacts.

Despite the concrete characteristics of the dispersed field of study, the position of being an outsider is also unavoidable in relationships with medical professionals when one is not a medical professional or even a member of that community of practice. Just like the patients, I felt like an outsider during the fieldwork when I did not understand the medical terminology. However, unlike most patients, I could look up terms from a medical dictionary.

The terminology is not only a linguistic problem, it also concerns a lack of knowledge about the social practice of medicine. Being in a position of not having the knowledge, I often felt stupid or even naive when I asked questions that were self-evident from the professionals' point of view. In the subsequent discussion, I am being informed about the practice of cooperation between primary and secondary care, which the specialist considers to be unproblematic. However, in a particular patient case, the cooperation was not functioning well. The discussion shows that I position myself as an outsider; the professional does not put me in that position.

Specialist: But there are huge numbers of recommendations about this [collaboration between primary and secondary care], about what should be followed up and treated where. These are many times ---

Researcher: So, it is these clinical practice guidelines?

Specialist: Yes.

Researcher: Okay.

Specialist: And there are also agreements about the levels of care.

Researcher: And they should be aware of them [at the primary care].

Specialist: Yes, they should (...). If twenty regulations do not do the job neither does the twenty-first one. There are quite many of these recommendations on diabetes on the state and regional levels. (...) And it is not even [pause] Do you, by the way, how many of them do you have in the first place?

Researcher: I do not have them, I have studied them on a general level only. So, I do not have the training for health care or medicine. In a way **I am an outsider** here. (June 6, 2001)

Becoming an insider in this study meant becoming more involved with the problems related to the patients' care and helped me to see the organization of care from an insider's perspective. From that perspective, the organization of care did not always seem sensible and meaningful. For instance, observing the disjunctions in the patients' care provision felt frightening and corroded my trust in the system of health care, although I met many skillful practitioners during my fieldwork.

In the project, we often observed the disjunctions in the patients' care provision as a consequence of the lack of cooperation between providers. Different perspectives on the patient's care provision often indicate disjunctions in the provision of care. When I would occasionally notice a disjunction in the care provision and the patient was not present, I usually brought it up in the discussion with the professionals. The painting in figure 7.3 captures the stage of the research process when I felt I was carrying messages in the "underworld" between patients and practitioners and between different practitioners.



Figure 7.3 "In the 'underworld'"

The Change Laboratory method also includes the movement between the field and the laboratory setting. Usually the synchronization of field data occurs after the fieldwork and before the laboratory meetings when the research group works with the “mirror” data. The movement between the fieldwork of the lonely researcher and the one of the researcher group is also embedded in the Change Laboratory setting. Moreover, the opportunity to reflect on the fieldwork in the research group enables the researcher to immerse in fields that may appear difficult or even painful.

The distinction between entering and leaving the field is not as clear as is often presented in ethnography. Further contact with the subjects in the field does not end when the fieldwork is completed. I had contact with some of the patients and professionals after the fieldwork ended. Besides sharing everyday matters, we discussed my findings in the study. Sometimes I even asked their opinions of my representations of the findings.

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