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Being an Austrian mother with rheumatoid arthritis: An institutional ethnography about the social organization of everyday life

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A thesis submitted in partial fulfillment of the requirements for the Doctor of Philosophy degree in Health and Rehabilitation Sciences

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**Being an Austrian mother with rheumatoid arthritis:
An institutional ethnography about the social organization of everyday life.**

(Spine title: Everyday life of Austrian mothers with rheumatoid arthritis)

(Thesis format: Monograph)

by

Birgit Prodinger

Graduate Program in Health and Rehabilitation Sciences

A thesis submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy

The School of Graduate and Postdoctoral Studies
The University of Western Ontario
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Abstract

This institutional ethnography research explored how women with rheumatoid arthritis, who are mothers, and of employable age, go about their daily lives given their social context. The social context for this research was Austria, which is characterized by social policies based on familialism and an emphasis on employment. This context may open up various resources and possibilities about what women can do and actually do in their daily lives, and thus, directs attention to the situated nature of human occupation.

In institutional ethnography particular attention is given to the social, which suggests that daily life becomes accomplished through coordinated activities of various individuals who are active across places and time. These social relations often remain invisible. Institutional ethnography aims to explicate these social relations by exploring the work, that is, anything that requires time, effort, and has intent, of individuals in their daily lives. An understanding of the work of the seven women in going about their lives was collected by means of interviews and participant observations. Texts were analyzed to understand how the actual, local doings of the women are coordinated to trans-local relations. Texts have a mediating character and coordinate the women's consciousness into relations ruling organizational processes.

The findings contain a thick description of the women's actual work in their daily lives; an explication of how their doings are coordinated to the relations ruling arthritis-related health care; and relations organizing processes related to employment and invalidity. What the women do, how they do it, and with whom, depends on how they are situated within social relations. Once they enter arthritis-related health care, their experiences become coordinated to medical concepts ruling these particular relations; once the women enter relations at the labor market, the concept of employability rules the processes there. Within these respective ruling relations, the complexity of the women's daily lives is not accounted for.

This research illustrates the necessity for attending to the situated nature of how individuals go about their daily lives to comprehensively understand the social organization and work that goes into accomplishing the ordinary activities of everyday life.

Keywords

Institutional ethnography, rheumatoid arthritis, Austria, women, occupation, employment, familialism, occupational science, ruling relations, health care;

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Table of Contents

CERTIFICATE OF EXAMINATION	ii
Abstract	iii
Acknowledgments.....	v
Table of Contents	vii
List of Tables	xi
List of Figures	xii
List of Appendices	xiii
List of Abbreviations	xiv
Glossary	xvi
Chapter 1	1
1 Introduction.....	1
1.1 The structure of this dissertation.....	3
1.2 The Austrian context.....	6
1.2.1 The Austrian health care system	6
1.2.2 The Austrian social welfare system	10
1.3 Situating the daily life of women within the Austrian system.....	19
1.4 Situating this dissertation in occupational science.....	22
Chapter 2.....	28
2 Daily life of women with rheumatoid arthritis.....	28
2.1 The medical condition of rheumatoid arthritis.....	28
2.2 The complexity of the daily life of women with rheumatoid arthritis.....	31

2.3	Women with rheumatoid arthritis and arthritis-related health care	39
2.4	The reduction of the complexity of daily life into individualized accounts	42
Chapter 3	45
3	Going beyond the <i>individual</i> – attending to the <i>social</i>	45
3.1	A social perspective on rheumatoid arthritis	46
3.2	Social perspectives on managing daily life with rheumatoid arthritis.....	49
3.3	The need for research about the situated nature of how Austrian women with rheumatoid arthritis go about their daily lives	54
Chapter 4	57
4	Institutional ethnography: A conceptual framework for inquiry	57
4.1	Starting with women’s experiences	57
4.1.1	The standpoint of women.....	58
4.1.2	The ontology of the social.....	59
4.2	Social relations.....	61
4.2.1	Ruling relations	64
4.2.2	Language and discourse	65
4.2.3	Agency and subjectivity.....	67
4.3	Studying what individuals do in daily life	68
4.4	Translating the conceptual framework into research: The work of Austrian mothers with rheumatoid arthritis.....	70
4.4.1	The problematic guiding this institutional ethnography	71
4.4.2	Research relations	73
4.4.3	Informants	77
4.4.4	Data collection	79
4.4.5	Analytical description	85

4.4.6	Ethical considerations	87
4.4.7	Rigor in institutional ethnography	89
4.4.8	Presentation of analytical descriptions.....	91
Chapter 5	92
5	Ethnographic accounts of the women’s daily life	92
5.1	Getting the work of daily life done	92
5.1.1	Getting started in the morning	93
5.1.2	Arranging one’s place	95
5.1.3	Preparing food for the family.....	96
5.1.4	Using transportation.....	98
5.2	Being a mother	100
5.3	Being cared for.....	103
5.4	Sustaining well-being.....	105
5.5	Discussion	107
Chapter 6	110
6	The ruling power of arthritis-related health care.....	110
6.1	The work setting of arthritis-related health care	110
6.2	The organization of the production of hospital records	113
6.3	The ruling of the women’s work in the setting	121
6.3.1	Authoritative knowledge.....	124
6.3.2	Complementary treatment.....	128
6.3.3	The textual production of the informed patient	130
6.4	Discussion	137

Chapter 7	142
7 Negotiating textually-mediated realities related to employment	142
7.1 Maintaining ‘employability’	143
7.2 Managing ‘invalidity status’	151
7.3 Resisting ‘disability’	155
7.4 Discussion	159
Chapter 8	163
8 The everyday life of Austrian women with rheumatoid arthritis – Some concluding remarks	163
8.1 The taken-for-granted in the daily lives of Austrian women	165
8.2 Daily life of Austrian women with rheumatoid arthritis ruled in different relations	167
8.2.1 Engaging in dialogue about what can be known and is known	170
8.2.2 Attending to the experiences of individuals	171
8.3 Implications for occupational science	172
References	176
Appendices	194
Curriculum Vitae	208

List of Tables

Table 1: Organization of the Austrian social insurance institutes	11
Table 2: Options for flat-rate child care allowance	18
Table 3: Information about informants	78
Table 4: Track of interviews and participant observations	83
Table 5: Main texts included in analytical description	85
Table 6: Eligibility criteria for unemployment benefits and social assistance	144

List of Figures

Figure 1: Financing of hospital-based and community-based health care provision.....	8
Figure 2: Illustration of the problematic	72
Figure 3: Processes of a routine visit in arthritis-related health care	113
Figure 4: The coordinated work of producing hospital records.....	114
Figure 5: Illustration of List of service codes	115
Figure 6: Illustration of Evaluation form	116
Figure 7: Coordination of texts within the hospital records	117
Figure 8: Documentation form for joint assessment.....	118
Figure 9: Structure of Information letter about drugs	132
Figure 10: The organization and coordinated work of a Consultation agreement at the labor market office	146
Figure 11: The textually-mediated organization of maintaining ‘invalidity status’	153

List of Appendices

Appendix 1: Interview guide for initial interview	194
Appendix 2: Interview guide for final interview	196
Appendix 3: Examples of mind maps	198
Appendix 4: Question guide for participant observations	200
Appendix 5: Guide for field-journal	202
Appendix 6: Ethics Approval notice.....	203
Appendix 7: Letter of information and consent form	204

List of Abbreviations

ACR	American College of Rheumatology
AK	Chamber of Labor (Arbeiterkammer)
AMS	Labor Market Office (Arbeitsmarktservice)
ASVG	General Social Insurance Act (Allgemeines Sozialversicherungsgesetz)
BASB	Federal Office for Social Affairs and Disability (Bundessozialamt)
BGStG	Austrian Federal Act on the Equalization of Persons with Disabilities (Behindertengleichstellungsgesetz)
BMASK	Federal Ministry of Labor, Social Affairs and Consumer Protection (Bundesministerium für Arbeit, Soziales und Konsumentenschutz)
BMG	Ministry of Health (Bundesministerium für Gesundheit)
BMWFJ	Federal Ministry of Economy, Family, and Youth (Bundesministerium für Wirtschaft, Familie und Jugend)
CDAI	Clinical Disease Activity Index
DA	Disease Activity
DAS	Disease Activity Score
DMARD	Disease-modifying anti-rheumatic drug
DRG	Diagnostic-related group
EU	European Union
EUR	Euro (Austrian currency)
EULAR	European League Against Rheumatism
HAQ-DI	Health Assessment Questionnaire – Disability Index
HSREB	Health Sciences Research Ethics Board
ICD-10	International Classification of Diseases (10 th Revision)
MUW	Medical University of Vienna (Medizinische Universität Wien)
NSAID	Non-steroid anti-inflammatory drug

ÖGR	Austrian Society for Rheumatology and Rehabilitation (Österreichische Gesellschaft für Rheumatologie und Rehabilitation)
ÖVP	Party of the Christian Democrats (Österreichische Volkspartei)
RA	Rheumatoid Arthritis
REB	Research Ethics Board
RIS	Legal Information System of the Republic of Austria (Rechtsinformationssystem)
SIN	Social insurance number
SOAP	Subjective/ Objective/ Assessment/ Plan (Structure for documentation in hospital records)
SPÖ	Party of the Social Democrats (Sozialdemokratische Partei)
SV	Social insurance; also social insurance institute (Sozialversicherung)
UK	United Kingdom
US	United States
VAS	Visual Analog Scale
WHO	World Health Organization

Glossary

Concept	Definition
Accomplishment	The notion of “accomplish” refers to the ethnomethodological influence in institutional ethnography. This notion puts attention to how commonsense, familiar activities are concerted and organized in everyday life so that they become recognized as ordered social scenes (de Montigny, 2007; Garfinkel, 1967).
Accountability	Accountability refers back to the ethnomethodological influence in institutional ethnography. Garfinkel referred to activities that are accountable as those that are observable and reportable. More specifically he outlines that “any setting organizes its activities to make its properties as an organized environment of practical activities detectable, countable, recordable, reportable, tell-a-story-aboutable, analyzable – in short, accountable” (Garfinkel, 1967, p. 33).
Authoritative knowledge	When experiences become subordinated to authorized objectified accounts, the knowledge that rules these accounts is named authoritative knowledge (Smith, 1990b).
Biometrician	Biometrician refers to a team of health professionals (e.g. occupational therapists, physiotherapists, nurses, and psychologists) at the Department of Rheumatology at the Medical University of Vienna, Austria, that is responsible for conducting routine and research-specific assessments and evaluation at the clinic.
Discourse	Discourse, as mediated through text, images, and language, coordinates the experiences and activities of various individuals into a common “sequential grammar” (Smith, 1999, p. 124). “What can be spoken or written and heard and understood by others” (Smith, 2005, p. 18) is

shaped through discourse. Hence, discourse is remade and reproduced through actual practices that are going on at various sites (Smith, 1999; 2005).

Generalization/ generalizable	Generalization in institutional ethnography refers to the organization of local experiences into generalized ruling relations (Smith, 1987; Townsend, 1998)
Ideology	Ideology is a method of reasoning that goes back to Karl Marx. Thinking ideologically means to think in a distinct way that directs attention away from actual experiences and confines practices of thinking and reasoning to an abstracted and conceptual level (Smith, 1990a).
Informants	In institutional ethnography, informants offer their insights, information, and cues as to how their work is coordinated to institutional discourse. The experience of informants is the standpoint from which to explore the social and ruling relations in which their experience is situated and organized. Informants are not transformed into the objects of this study, but rather acknowledged as knowing actors (Smith, 1987).
Institution	Institutions refer to a functional complex; that is the organization of practices and activities around a distinctive function such as health care, mothering, or education (Smith, 1987; 2005).
Institutional capture	When informants' accounts of their experiences are converted into the terms of an institutional discourse, institutional ethnographers refer to institutional capture (McCoy, 2006). Institutional capture may occur when researcher and informants are both familiar with the institutional discourse and remain talking within the institutional discourse rather than attending to the actual work and experiences of the informant (Smith, 2003).

Knowledge	Work knowledge describes the knowledge that people have “of and in their work and how it is coordinated with the work of others” (Smith, 2005, p. 229)
Local	The local refers to the place where individuals are active with their bodies in actual place and time. Local settings are organized by social relations that go beyond the local setting and extend to trans-/ extra-local settings. This trans-/ extra-local relations shape the local setting. Exploring how daily life becomes accomplished in local settings, and tracing extra-/ trans-local relations, facilitates the understanding of the social organization of everyday life (Grahame & Grahame, 2009; Smith, 1987; 2005).
Materiality	The materiality of daily life underscores that daily life takes place under definite conditions, in actual time at an actual place (Smith, 1987; 2005).
Occupation	Occupations are “the various everyday activities people do as individuals, in families and with communities to occupy time and bring meaning and purpose to life. Occupations include things people need to, want to and are expected to do” (ISOS, 2011)
Problematic	The problematic constitutes the area to be discovered in institutional ethnography. "The problematic of the everyday world arises precisely at the juncture of particular experience, with generalizing and abstracted forms of social relations" (Smith, 1987, p. 187).
Remission	In reference to rheumatoid arthritis, remission is “a state with no apparent disease activity and absence of joint damage and disability progression” (Villeneuve and Emery, 2009, p. 110).

Rheumatoid arthritis	Rheumatoid arthritis is a chronic, systemic inflammatory disease that may affect people at any age. Characteristically, the highly destructive nature of rheumatoid arthritis starts with the inflammation of joints. Persistent synovitis may lead to the development of joint damage in the respective joint that leads also to severe pain early in the course of the disease (Smolen & Aletaha, 2004; Smolen & Steiner, 2003; Turkiewicz & Moreland, 2006).
Ruling relations	Ruling relations develop historically and are forms of consciousness that cannot be conceived as arising in the daily lives of individuals but rather coordinate the activities of many people whose consciousness is coordinated to and shaped by these relations. Exploring the ruling relations is exploring particular forms of power that are diffused through textually-mediated social relation. The ruling relations are not something abstract existing “out there”. Rather, it is the ruling relations that abstract the activities of the individual in everyday life into a “technological and technical specialization, elaboration, differentiation, and objectification“ (Smith, 1999, p. 77).
Situated nature	The situated nature of what individuals do in their daily lives refers to “how occupation is shaped, embedded and negotiated within, as well as how it contributes to the shaping of, social systems and structures” (Laliberte Rudman, 2010, p. 55)
Social	<p>The term ‘social’ is used in distinctive ways throughout this dissertation:</p> <p>First, in reference to the ontology of the social: In regard to institutional ethnography, the reference is to the ontology of the social, which attends to the ongoing activities of people by looking specifically at how things are coordinated with the activities of other people. The social characterizes the coordination of people’s activities</p>

in local and extra-local settings. Attention is given to the social relations that describe how the activities of individuals are socially organized across time and place (Smith, 1999; 2005).

Second, in terms of features of a welfare state: When used as an adjective, for instance social insurance, social systems, social structures, the reference is to structures built through or services provided and/ or supported by the welfare state. Examples are benefits and services provided to people who are unemployed or on sick-leave, or family benefits.

Third, as a social perspective: My reference to a social perspective implies that attention is given not primarily to the individual, but to the interface of the individual and the social context and how the disease is negotiated and shaped at this interface. A social perspective is concerned with the social construction of certain phenomena, as well as with for instance the accessibility, availability, and distribution of services and resources to individuals given their social context.

Social organization Social organization refers to the reproduction of particular social relations over and over again (Smith, 1999; 2005).

Social relations Social relations are based in the Marxist tradition and refer to connections between and coordination of people and work processes at various sites. By focusing on the social relations, the researcher is oriented toward sequences of action that extend to trans-/ extra-local sites (DeVault, 2008).

Social situatedness My reference to social situatedness is close to DeVault's understanding of social class as "dynamic social process, organizing the activities of individuals and families both in very direct ways – such as through wages flowing into households, or the demands of particular occupations – and also in less direct ways, through locations in

particular neighborhoods, schools, and other social groups” (1991, p. 168; Note: DeVault's understanding of occupation refers to one's profession and is not necessarily in line with occupational scientists and therapists understanding of occupation).

Standpoint Institutional ethnographers start inquiry at the standpoint of individuals in their daily lives, that is, inquiry starts at the experiences of individuals rather than subordinating their experiences to objectified forms of knowledge. The notion of standpoint points attention to the everyday life; it returns to the actualities where actual people go about their daily life in real life (Smith, 1997; 2005).

Texts Texts are any kind of document, photograph, drawing, video, sound recording, or representations that have a fixed and replicable character. They include any documents that can be stored, copied, transferred and distributed to become subsequently activated by users at different places at different points in time. Given these characteristics of texts, they have a standardizing and mediating role in the social relations. Texts occur in time and space, constitute and organize actions and courses of actions, and mediate knowledge that is the property of organizations rather than individuals. Texts are replicable and mediate discourses and ruling relations (DeVault and McCoy, 2002; 2006; Smith, 1987; 2005).

Work Work is used in two distinct ways in this dissertation:
First, it is used in the institutional ethnography sense: For institutional ethnographers, work encompasses any activity that people do that requires time and effort, and has intent. This concept “wants to include the actual doings that go on to making institutions happen, whether they are recognized in institutional discourse or not” (Smith, 2005, p. 157). The reference to work acknowledges the subjectivity of the individual who is doing the work; this all-encompassing reference to

work goes back to the women's movement and the attempt to make the everyday work that women do visible (Smith, 1987; 2005).

Secondly, it is used in terms of employment or paid work. As such, it appears also in regard to for instance work disability or work-place.

Work
knowledge

Work knowledge refers to what individuals know in and of their work, and how their work is coordinated with others. Institutional ethnographers draw upon people's work knowledge as a major source for discovering how daily life is socially organized (Smith, 2005).

Chapter 1

1 Introduction

I aimed to explore in my dissertation how Austrian women, who are mothers, of employable age, and have been diagnosed with rheumatoid arthritis, are going about their everyday life as it is situated within their social context. More specifically, I was interested in understanding how the social context, including organizational processes in for instance arthritis-related health care, may open up varying resources and possibilities for what the women can do and actually do. My dissertation research started at the disjuncture that I have experienced as an occupational therapist in working in a rheumatology outpatient clinic: what women, and in particular mothers, were describing about their everyday lives did not fit into the standardized categories of routine assessments that I was supposed to fill in. I became concerned about what occupations¹ of the women's daily lives become addressed in arthritis-related health care as well as which occupations remained unaddressed and were thus left for the women to struggle with on their own. Despite a vast body of literature on the impact of the disease on women's lives, on changes and adaptations required when living with the disease over time, and on the availability and advancements of comprehensive treatments for people with rheumatoid arthritis, I could find little literature that addressed how women with rheumatoid arthritis actually manage their everyday life as it interacts with various organizational processes including health care.

As I felt limited in understanding this disjuncture, I went to literature that approaches illness and disease from a social rather than medical perspective. Literature from a social perspective calls attention to the interface of the individual and the social context and how the disease is negotiated and shaped at this interface. A social perspective is concerned with the social construction of certain phenomena, as well as with, for

¹ Occupations refers in this dissertation to “the various everyday activities people do as individuals, in families and with communities to occupy time and bring meaning and purpose to life. Occupations include things people need to, want to and are expected to do” (ISOS, 2011).

instance, the availability and accessibility of services and resources to individuals given their social context. For instance, research on social determinants points to the importance of considering the life conditions and circumstances of individuals to comprehensively understand the health of individuals across their life course. In contrast to the dominant approach to knowledge generation in arthritis-related literature that focuses predominantly on the individual and the medical condition, literature from a social perspective directs attention to society and how disease is negotiated and shaped at the interface of the individual and social context. Thus, both approaches are relevant, and yet limited, for achieving a more comprehensive understanding about what the women actually do in their daily lives and what becomes addressed within organizational processes such as arthritis-related health care.

My aim of exploring how Austrian women with rheumatoid arthritis go about their everyday lives was informed by the disjuncture that I was experiencing between what they described about their daily lives and what was attended to in arthritis-related health care. In this research, I was interested in understanding, from the women's knowledge and experiences how they go about their everyday life, in particular, how their doings are coordinated to organizational processes such as arthritis-related health care. Throughout the course of my doctoral studies I came to know institutional ethnography, which provides a conceptual framework for inquiry that acknowledges the social situatedness of people and their everyday activity (Smith, 2005). Institutional ethnographers aim to explore and understand how the complexity of everyday life is put together into a complex whole. The starting point of institutional ethnographers is the standpoint of individuals, the experiences of actual people as they are active in their daily lives. I started in this dissertation from the experiences of women with rheumatoid arthritis as they are active in their daily lives to explore how their work² is coordinated with other people and organizational processes. Addressing how their work is coordinated with others and broader processes calls attention to the women's situatedness given their social

² For institutional ethnographers, work encompasses any activity that people do that requires time and effort, and has intent (Smith, 1987; 2005).

context and the subsequent resources and possibilities for what they do and can do in their daily lives. Equally I am drawing upon my knowledge about the organizational processes within arthritis-related health care gained through my experience of working in a rheumatology outpatient clinic. This knowledge provided me with a complementary perspective about how the activities of various people, such as patients and health professionals, are coordinated in such a clinical setting.

1.1 The structure of this dissertation

In this dissertation I drew upon my clinical and work experience in the field of Rheumatology in Vienna (Austria) and the research I conducted in Austria. The dissertation was written as part of my doctoral studies at The University of Western Ontario in Canada. As I wrote this dissertation I kept an international audience in mind and made an effort to familiarize international readers with the Austrian system. Hence, I begin by providing a brief overview about key-tenets of the Austrian health care and social system in the next section of this chapter. My experience as an occupational therapist and a doctoral student in occupational science is also crucial to the understandings gained through this study about how women with rheumatoid arthritis go about their everyday lives. Hence, I conclude this first chapter with my reflections on how I understand occupational science and see my research contributing to occupational science, as well as how this knowledge can further the understanding about how women go about their daily lives as they are situated within their given social context.

After outlining the Austrian and disciplinary context for this research, I present in chapters two and three a review of relevant literature addressing the daily lives of women with rheumatoid arthritis, with chapter two outlining literature within the dominant approach to knowledge generation in arthritis-related literature, and chapter three addressing a social perspective. The review of this literature on the everyday lives of women with rheumatoid arthritis was guided by the aim of this research, namely to explore how women with rheumatoid arthritis go about their daily life as it is situated within their social context. Despite the vast amount of research drawing on these two broad perspectives, the literature that addresses the interrelation of the two perspectives is very limited. I argue that the literature falls short in offering an understanding of how

women with rheumatoid arthritis actually go about their daily lives, given that the disease might be one part of a complex whole. I am using the daily lives of women with rheumatoid arthritis as a thread throughout the literature review to argue that research is needed that starts in the actualities of women with rheumatoid arthritis and their doings as they are situated within a particular social context. This context opens up various resources and possibilities for what women can do in their daily lives and what they actually do. Thus, the purpose of the literature reviews is not solely to review relevant literature from a medical, rehabilitation, and social perspective respectively; it is to elaborate and subsequently build on insights gained from each perspective to argue for the relevance of my research inquiry.

The overall structure of these two literature review chapters is similar: at the beginning of each chapter a short introduction is given about the main arguments addressed in the chapter, followed by the elaboration of these arguments based on current literature. Both chapters conclude with a discussion on what remains unattended in current literature regarding the daily lives of women with rheumatoid arthritis. Based on the review of the literature I posit that an approach is needed that acknowledges the situated nature of women's doings in their everyday lives, that allows for better understanding the complexity of women's lives and at the same time does not lose sight of the social context. I therefore posit institutional ethnography as one promising approach.

Chapter four introduces institutional ethnography as the conceptual framework for inquiry drawn upon in this dissertation. This chapter is divided into two parts. First, I introduce the framework for inquiry informing institutional ethnography. In the second part I outline how this framework guided this research and present the detailed research process of this study.

In chapters five to seven the analytical descriptions and insights gained from my research are presented; in each chapter I outline a distinct analytical focus and conclude with a short discussion about the specific findings in reference to reviewed literature. In chapter five I present an ethnographic account based on interviews and participant observations

of what the women are doing in their daily lives. This chapter starts with the informants,³ experiences and work knowledge as they go about their daily lives. The analytical description presented in chapter six focuses on the organization of arthritis-related health care as it is textually-mediated through the hospital records. In this chapter I analytically describe the hospital record as a sequence in time, a course of action, to explicate how the work of health professionals and the informants is coordinated and organized in this work setting. Furthermore, based on the women's accounts I outline what remains unattended within the ruling relations in arthritis-related health care. Chapter seven addresses the work that women do regarding employability, invalidity/ capacity to work, and disability. In this chapter the analytical focus is on how higher-order texts, such as law-texts, infiltrate into the work of people active in this work setting, and mediate the consciousness of service agents and the women into the relations ruling social services related to unemployment and invalidity. Moreover, I illustrate the work that women were doing to resist being labeled disabled, and how this work is shaped by and reflects the historical development of disability policies.

In the analytical description presented in chapters five to seven the diversity of informants' work knowledge becomes evident given their situatedness within the social relations and their unique resources and needs. At the same time, the textually-mediated realities of arthritis-related health care and employment related matters coordinate their work into standardized ruling relations. Only work that fits within the abstracted and conceptual work of the ruling relations would become accounted for, that is any activity that fits within the boundaries of concepts and can be reported and recorded within these conceptual boundaries. Work not fitting into these concepts remains unnoticed and unattended.

In chapter eight I revisit the disjuncture from which I started this research, and discuss and reflect upon how this research allowed furthering the understanding of the situated nature of occupation by taking the social context into consideration, and address some

³ In institutional ethnography participants in research are referred to as informants (Campbell & Gregor, 2004).

implications emerging from this research. I close this dissertation with my thoughts on how institutional ethnography offers a useful and promising framework for inquiry to advance the knowledge about the situated nature of what people do in their daily lives in occupational science. Given the focus of my research, I predominantly used the female form throughout the dissertation when referring to individuals with rheumatoid arthritis and their situatedness within the social context.

1.2 The Austrian context

In providing the context for this research, I start with placing the clinical setting, in which the disjuncture that evoked the interest in this thesis emerged, within the structure of the Austrian health care system. In subsequent chapters, key structural characteristics of the Austrian health care and social system are drawn upon when referring to the situatedness of the daily lives of Austrian women with rheumatoid arthritis. Thus, the description of the Austrian health care and social system provides some background information about the social context that shapes the daily lives of the women who participated in this research for an international audience.

1.2.1 The Austrian health care system

My clinical experience most relevant to this dissertation research evolved when I was working as an occupational therapist in a rheumatology outpatient clinic in Vienna (Austria). Women who participated in this research were also recruited from this clinic. This outpatient clinic is linked with the Medical University and a public hospital. As a department within the Medical University, the department is committed to research and has been recognized for its continuous research in the field of rheumatology. The clinic has been identified as Center of Excellence by the European League Against Rheumatism (EULAR, 2012), a designation granted based on an outstanding record of scientific contributions to the field. The linkage with the university indicates that the clinic is a teaching clinic as well. Health professionals, in particular medical doctors in specialized training, are engaged at the clinic for a certain period of time, and then rotate further to another department. This has implications for a woman with rheumatoid arthritis as she may consult with a different doctor any time she attends the clinic.

The fact that the clinic is attached to a public hospital has implications for funding and service provision. An outpatient clinic attached to a public hospital is regulated under the state law and implies that services offered at this clinic are not offered elsewhere or within reasonable distance for patients (RIS, 2011). This implies that patients consulting this clinic do not only come from the immediate urban catchment. In Austria seventy percent of hospitals are public hospitals financed directly through taxation (about 25 percent are run by non-for-profit organizations, and about five percent by private for-profit organizations; Busse, Saltman, & Dubois, 2004). In the Austrian health care system, parallel access to primary and specialist care is assured with no geographical restrictions (van der Zee & Kroneman, 2007). No geographical restriction means that individuals can consult any health professionals in primary or specialist care not only in their home province, but also in other provinces. Patients have the right to access any physician directly regardless of the district or province. Parallel access implies that a woman with rheumatoid arthritis can consult any specialist without the necessity of a referral from her general practitioner. A physician's referral is needed though to access health professionals such as occupational therapists or physiotherapists, as it is regulated by law that health professionals are only allowed to treat patients based on a physician's referral (Stamm, 2009).

In Austria, hospital and community-based health care are grounded in two different financing schemes as illustrated in Figure 1. I am referring here to 'community-based' health care as any primary and secondary health care that is provided by medical and health professionals located outside hospitals. As an outpatient clinic attached to a public hospital, the rheumatology outpatient clinic is also financed through a hospital-based funding scheme, hence, I refer to it also as being hospital-based.

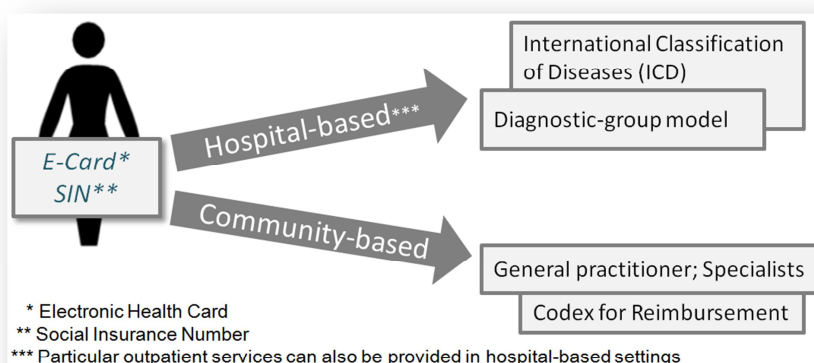


Figure 1: Financing of hospital-based and community-based health care provision⁴

In the case of community-based care, the Federation of all social insurance institutes provides a Codex for Reimbursement that outlines services that are covered within public health care. For instance, the Federation of all social insurance institutes has generated a database with a list of pharmaceuticals that are covered by sickness funds for purposes of monitoring and quality management. For some prescribed special medication, authorization by a senior physician (Chefarzt) is required (BMASK, 2010b). The database which goes into the Codex for Reimbursement is structured by a box-system to ensure most cost-effective prescriptions. Any pharmaceutical covered in the database is assigned to either red, yellow, green, or no box; any medication in the red or yellow box requires the approval of a senior physician of the sickness fund before the prescription is valid (Hofmarcher & Rack, 2006). This means that a woman with rheumatoid arthritis who receives a prescription that falls into the red or yellow box has to see the senior-physician of the sickness fund she is assigned with and get approval for her medication before she can actually go to the pharmacy to pick the medication up.

⁴ Figure 1 was developed within the scope of this dissertation.

Hospital-based health care, on the other hand, is based on a diagnostic-related group funding (DRG; BMG, 2010b). This funding model indicates that once somebody is diagnosed with a disease according to the International Classification of Diseases (ICD-10; WHO, 2011a) then sickness funds would cover predefined health care services.

Sickness funds are a powerful player in the Austrian health care system as they are collector of revenues and payer of services. Sickness funds cover allowance in kind (e.g. medical treatment, medication, aids and assistive devices), and monetary allowance (e.g. weekly allowance, sickness benefit) (BMG, 2010a). Individuals, who are health insured through sickness-funds, have a right of timely unlimited in-patient health care in hospitals. If a person is hospitalized, a daily fee of 7 to 17,30 Euros is charged. Individuals have to pay costs up to a maximum of 28 days per year; thereafter, it is covered via insurance. People with identified social needs are exempted from this fee (BMASK, 2010b). Regarding medication, a predetermined fixed prescription fee of five Euros has to be paid by the individual for any medication. People with low income or people with expenditures for medication above average, which may include persons with rheumatoid arthritis, can apply for release of this fee. In January 2008 a cap was introduced, such that individuals who have already paid more than two percent of their net income per year for medication fees receive also a release for the remaining year.

Increasing critique has been raised about the fragmented service provision and the lack of coordination between hospital-based and community-based health care (Wendt & Thompson, 2003). For a woman with rheumatoid arthritis who receives health care, the separation between hospital and community based health care becomes apparent for instance when she receives a prescription for medication from the rheumatology outpatient clinic. As the outpatient clinic is attached to the hospital, the rheumatology outpatient clinic is financed based on the performance-based diagnostic group model. However, once the patient would like to pick up the medication in the pharmacy, she does not necessarily know whether the prescribed medication is covered through her sickness fund. She is supposed to go to the General Practitioner first, who reviews whether the medication is covered within the Codex of reimbursement and revises the

prescription if necessary. If the medication falls into the red or yellow box, she may have to consult additionally a senior physician of her sickness fund.

In addition to the critique of the fragmentation of hospital-based and community-based health care, further issues and challenges within the Austrian health care system have been raised by the Federation of Austrian social insurance institutes (SV, 2010). In particular the lack of a cross-sectoral planning and provision of services has been identified as an issue. The cross-sectoral planning and provision of services points to the provision of social welfare. Social welfare is understood as the state's role and responsibility in providing some basic modicum of welfare to its citizens, including the domains of health, but also social insurance and services, and poor relief (Eikemo & Bambra, 2008). Social welfare is framed within the structure of the Austrian social insurance based system.

1.2.2 The Austrian social welfare system

The Austrian social welfare system is grounded within a social insurance based system (Ivansits & Pfeil, 2010). The social insurance system has a long history in Austria as core branches of social insurance were already introduced in the late nineteenth century (Obinger et al., 2010). It currently exists as a Federation of social insurance institutions and contains accident, health and pension insurance schemes (Table 1). Unemployment constitutes another important dimension within the Austrian social insurance system. In contrast to accident, health, and pension insurance, unemployment insurance is regulated by an independent organization and characterized by a distinct service- and provision scheme. Further details in this regard are outlined in this chapter's section on Unemployment benefits and social assistance.

Federation of Austrian social insurance institutes			
Accident insurance	Health insurance		Pension insurance
General institute for accident insurance	9 provincial sickness funds	6 sickness funds for companies	Pension insurance institute
	Social insurance institute for industry (incl. self-employed people)		
Social insurance institute for farmers			
Social insurance institute for railway and coal mining			
Social insurance institute for civil servants			Social insurance institute for notary

Table 1: Organization of the Austrian social insurance institutes⁵

The supervision of the various insurance schemes is assigned to the following Ministries (European Commission, 2011):

- Health and accident (refers to work-related injuries and occupational diseases) insurance to the Federal Ministry of Health
- Pension insurance (includes old age, invalidity, and death) to the Federal Ministry of Labor, Social Affairs and Consumer Protection (BMASK).
- Unemployment insurance is directed by the labor market service (AMS) which operates under the supervision of the BMASK.

Thus, one way in which cross-sectoral planning and service provision is challenged is the administration of different insurance schemes by different ministries.

Assignment to social insurance institutes occurs in various ways: in the case of sickness funds for companies based on the employer; in the case of funds for particular professions based on professions or professional status, such as farmers, railway employee, or civil servants; or in the case of provincial sickness funds on the basis of region of the employer's residence. This structure of the social insurance system leaves individuals with basically no choice about the social insurance institute (Busse et al., 2004).

⁵ Table 1 is based on a Figure in BMASK (2010b, p. 11) and has been translated and slightly modified.

Any individual that is born in Austria is assigned a social insurance number (SIN) immediately after birth. The SIN consists of 10 numbers (four numbers followed by the birth date; XXXX DDMMYY). Children until the age of 18 are co-insured with their parents except if the child takes on employment earlier; students until the age of 27 years can also be co-insured with their parents (SV, 2011). Once an individual takes up employment in Austria, the employer has to register the employee for social insurance purposes (European Commission, 2011). Women who are on maternity leave continue to be insured themselves; once maternity leave ends the woman takes on employment again and maintains her insurance status. If a woman decides to opt out of employment and stay at home with the child, she would have to become self-employed or is co-insured with her partner.

Individuals who have a total income below a “minimum threshold” of 374.02 Euros per month (as of 2011; SV, 2011) do not fall into the mandatory social insurance scheme, however, a special voluntary scheme is available for them. This is an option individuals have to opt into and pay for. Any individual who has social insurance has the right for social benefits and services. Each individual who has social insurance is provided an electronic health card (E-card) which serves as a proof for one’s health insurance status, and is essential for the accounting of costs with the physician with sickness funds (BMASK, 2010b). Sickness funds may vary in their service provision: for instance, individuals insured with the Provincial sickness fund have to pay an annual service fee of 10 Euros which is levied from the employers; settlement of costs occurs on a quarterly basis; and individuals can only change specialists on a quarterly basis. In contrast, individuals who are health insured with the Social insurance institute for civil servants have to pay a 20 percent excess of health services; however, they do not have to pay service fee for the electronic health card and individuals can change their doctor on a monthly basis (SV, 2011).

1.2.2.1 Social benefits and services

The Austrian welfare state provides various social services and benefits, which can be subdivided into benefits and services that refer to social compensation, needs-based provision, or to a provision based on a universal system (BMASK, 2009a). Provisions

based on a universal system are independent of previous employment or level of income and include for instance family allowance, child care allowance, and care allowance (BMASK, 2009a). In this section I outline the social benefits that are particularly relevant for the context of women with rheumatoid arthritis, which includes sickness benefits, unemployment benefits and social assistance, invalidity benefits, disability pass, and family benefits.

Sickness benefits

Sickness benefits are granted when sickness is evident based on the legal definition (based on § 120 Z1 ASVG); sickness entails abnormal physical or mental state which requires treatment (Ivansits & Pfeil, 2010). In case of sickness, the employer has to provide continuous payment up to a certain predetermined period. After that, the sickness fund covers continuous payment. The duration of continuous payment depends on the period of previous contributions to health insurance (up to max. 6 – 12 months). The minimum payment is 50 percent of the previous gross income. The individual can apply for invalidity pension if the disease lasts for longer than the period of continuous payment covered by the sickness fund. In Austria there is only the option of being on or off sickness benefits which may constitute a challenge in the case of diseases with a chronic, episodic nature such as rheumatoid arthritis. Self-employed people only receive continuous payments if they have a voluntary insurance for the case of sickness (BMASK, 2010b).

Unemployment benefits and social assistance

Unemployment benefits and social assistance are the most common monetary benefits out of unemployment insurance (BMASK, 2010b). The labor market office (AMS; Arbeitsmarktservice) plays a central role in the provision of unemployment benefits and assistance as it is located at the interface between the individual and the government. In 1994 with the inception of the Public law for the labor market service, the management of the labor market office was outsourced from the BMASK and is constituted since then as service provider under public law. The labor market office bears responsibility for preventing and remediating unemployment in Austria (AMS, 2011b). Labor market

policies comprise passive and active dimensions. The passive dimension includes the monetary compensation in case of unemployment (incl. unemployment benefits). Active labor market policies, such as re-training programs, play a less significant role in Austria than in other European countries (AK, 2011).

Unemployment benefits are insurance benefits, their value depends on previous insurance periods; however, additional payments would be granted if the benefits are below a predetermined minimum threshold. In order to receive unemployment benefits (BMASK, 2010b), an individual must

- have a record of a minimum insurance period: 52 weeks within a period of 24 months.
- be employable: otherwise the responsibility for providing benefits is with the health- or pension-insurance (e.g. in case of invalidity or unemployability).
- be willing to work and take on a reasonable job, that is, a job that fulfills all legal requirements and requirements based on collective bargaining agreement.

Statistics from 2009 indicate that mean unemployment benefits are slightly lower for women than for men which results out of differences in previous income and employment records. Maximum duration of benefits depends on previous insurance periods; for instance 20 weeks of benefits are granted based on a minimum insurance period; 30 weeks in case of 3 years of insurance period out of five years in total. Minimum insurance period refers to 52 weeks of social insurance within 24 months for people who apply for unemployment benefits the first time. Exceptions are available for people under 25 years of age, and people who have received benefits previously. Once benefits are granted for a determined period, an extension of benefits can be granted if an individual participates in active employment programs offered by the labor market office (e.g. re-training programs; BMASK; 2010b)

Social assistance is based on previously received unemployment benefits and the need for financial support. Thus, social assistance contains principles of social insurance and social welfare (AMS, 2011b). Any person that receives social assistance is also health insured (AMS, 2011b; BMASK, 2010b). This monetary assistance can be granted until an individual is granted pension, however, after 52 weeks an application for renewal has to be submitted to the labor market office. The family income, meaning the income that is

available in a given household, provides the foundation for the needs-base. In 2010, changes in the social benefits system were introduced with implications for social assistance: the amount is not solely dependent on previous unemployment benefits anymore, but also on the minimum threshold defined within the needs-based minimum social benefits system. In 2009, the mean social assistance was 25 percent lower than the mean unemployment benefits (AMS, 2011b; BMASK, 2010b).

The distinction between unemployment benefits and social assistance is also grounded in distinct paragraphs within Public act for Insurance of the Unemployed. Unemployment benefits direct back to §12 of this act which outlines that the unemployed person is an individual who discontinued employment, is not liable anymore to mandatory social insurance that underlies retirement pension insurance, and does not pursue any new or further employment. Social assistance benefits are addressed in §33 of the Public act for insurance of the unemployed and come into effect for unemployed individuals who have exhausted unemployment benefits.

Invalidity benefits

An individual can apply for invalidity benefits once her employability is deemed to be challenged. The terms invalidity and incapacity to work refer to blue-collar ('Arbeiter') workers and white-collar ('Angestellte') workers respectively (PV, 2012).⁶ People can apply for invalidity/ incapacity to work pension

- if they have no entitlement for rehabilitation or these efforts are not purposeful;
- if invalidity/ incapacity to work will last for at least 6 months;
- if they have a record of a certain insurance period;
- if they do not fulfill the criteria for old-age pension.

The degree of invalidity is determined within the frame of a medical examination by a certified doctor. If it can be assumed that the degree of invalidity/ incapacity to work is decreasing, then invalidity/ incapacity to work pension is granted for a fixed period of

⁶ I am using predominantly the term invalidity throughout this dissertation.

two years (SV, 2011). If the medical examination reveals possibility for reintegration into employment, rehabilitation would be initiated. Rehabilitation may include medical, vocational, and social measures/ actions: medical actions refer to rehabilitation in a respective institute or reimbursement for prostheses; vocational actions contain re-training other actions taken to ensure continuation of employment; social measures may include offering credit-lines for the adaptation of the apartment. Rehabilitation is not subject of being a legal entitlement. If invalidity is assumed to be not decreasing then unrestricted invalidity pension would be granted (PV, 2012)

Disability pass

Disability does not entitle the individual to receive social services and benefits such as unemployment or invalidity, but rather refers to efforts toward societal integration of people with disabilities. Nevertheless, as I have conducted my research with women of employable age, I consider it noteworthy to discuss disability in the context of unemployment, social assistance, and sickness as with the passing of the Austrian Federal Act on the Equalization of Persons with Disabilities (BGStG) in 2005 the Federal Office for Social Affairs and Disability (Bundesamt für Soziales und Behindertenwesen – Bundessozialamt; BASB) was established. The BASB is a service provider that is subordinated to the BMASK. Disability is seen to be a cross-sectoral task and has to be integrated into all political concepts and actions across sectors – the social integration of people with disabilities in any sector has been referred to as mainstreaming (BMASK, 2010a). As any sector aims for distinct outcomes, each sector has a distinct definition of disability which leads to a broad variety of definitions for disability within the Austrian law (BMASK, 2009a). The main areas of practice include the conduct of arbitration processes in reference to equality of people with disabilities, vocational integration of people with disabilities, and the support of informal caregivers (BASB, 2011).

People with disability can submit an application to the BASB for a disability pass. To be eligible for a disability pass, one has to have a degree of disability that reduces employability by at least 50 percent. Verification of this degree of disability is made through a medical examination by the Federal Office of Social Affairs and Disability (BASB). The disability pass is a card that serves as a proof for a particular degree of

disability and allows, for instance, for certain deductions at social and cultural events, and other transport-related expenses, as well as a flat-rate for income tax allowance (BASB, 2011). The disability pass does not imply that one belongs to the group of people with disabilities that are granted particular employment protections (Personenkreis begünstigt Behinderter). To become a member of this group a separate application has to be submitted to the BASB. Being granted the status of a person with disability with particular employment protections according to the Employment law for people with disabilities (Bundeseinstellungsgesetz; BEinstG) has legal consequences. Such consequences include particular obligations related to employment for employers and employees, as well as protection rights and financial implications (BASB, 2011).

Family benefits

Social benefits regarding families include co-insurance for family members, fiscal family support, infrastructure and allowance in kind (e.g. day care, free obligatory pre-school year, free medical provision for pregnant women and young children; provision of public playgrounds), entitlements grounded in labor law (e.g. nursing leave, maternity leave, protected leave of expecting women), and considerations of families in various social fields (e.g. free public school transport, discount for families for public transport and other public facilities) (AK, 2011). Within Austria, family benefits total up to 10 % of all social expenditures which is above the EU-average of eight percent (AK, 2011). For Austrian couples with children the most common pattern for reconciliation of work and child care in 2009 was the full employment of the father combined with part-time employment of the mother (BMASK, 2010b). The Federal Ministry of Economy, Family, and Youth (BMWFJ, 2011b) has released a variety of maternity and paternity leave models that aim to provide families, and in particular women, more choice in their efforts to reconcile their careers and family-commitments. About a quarter of all health insured people in Austria do not pay any contributions and derive their insurance status through their (predominantly married) partner or in case of children through their parents (Thomson, Foubister, & Mossialos, 2009). In 2002 parental leave benefits were replaced with child care allowance. Child care allowance is offered either as a flat-rate or based on income. Flat-rate child care allowance contains different options as outlined in Table 2:

Option	Months granted for the mother, until the child is ...	Additional months granted for the father	Amount per month (in Euro)
I	30 months old	6	436.00
II	20 months old	4	624.00
III	15 months old	3	800.00
IV	12 months old	2	1,000.00

Table 2: Options for flat-rate child care allowance⁷

The parent who receives flat-rate child care allowance is allowed to earn “an additional income equivalent of 60 % of the income generated in the calendar year prior to the year in which the child is born (...) or a minimum amount of EUR 16,200 may be earned” (BMWFJ, 2011a, p. 14). The flat-rate options are independent of prior employment in contrast to the income-based option:

“[I]ncome-based child care allowance amounts to 80% of the actual or notional maternity allowance. Based on an additional automatic comparison – a calculation done by the public health insurance fund – with the income from the calendar year before the year in which the child was born and in which no child care allowance was received (...) the daily rate may rise as the higher amount is used” (BMWFJ, 2011a, p. 16).

A maximum of 2,000.00 Euro of child care allowance is paid. Regardless of the option chosen, each option is linked with regular, predetermined medical examinations (mother-child pass scheme; examinations occur during pregnancy and five check-up visits once the child is born). Otherwise, child care allowance is halved after a predetermined period of time (BMWFJ, 2011a). The first option for flat-rate of 30 months brings some disadvantages for women as “the duration of the parental benefit exceeds the leave period which leads to the exclusion from protective labor market legislation attached to parental leave if the carer does not return to his/ her job after two years” (Leitner, 2003, p. 370).

⁷ Table 2 has been created based on information published in BMWFJ (2011a).

Despite these disadvantages, Austrian women most frequently use the first option in Table 2; however, their choices may have implications for their future social security status. The Austrian Minister for Women Affairs suggested skipping the first option as this option may bring particular disadvantages for women later on in their lives:

“as long as we live in a system in which people’s employment is the central requirement for independent social security of the individual, then responsible politics has to animate women to pay as long as possible into the respective insurance schemes. The opposite is to pretend to women that they have freedom of choice and then leave them standing out in the rain in all other areas of life” (Freudenschuss, 2011; personal translation: original document in German language).

Next to child care allowance, family benefits include also a protected leave for pregnant women. Protected leave is paid instead of their regular salary starting eight weeks prior to expected birth date and ending eight weeks after giving birth (BMWFJ, 2011a). Pregnant women are required to take this protected leave, this means that they must not work within this period. Individual prohibition to employment is also granted if the life of the pregnant woman and/ or the child’s life are threatened if she would continue work throughout pregnancy. Therefore a report from a certified physician or a representative from occupational safety and health administration has to be provided to the sickness fund which would subsequently compensate for individual prohibition to employment (SV, 2011). Moreover, family allowance is granted for any child once it is born until the child turns 24 years of age. If the child takes on employment before this age, then family allowance discontinues. The amount of family allowance varies depending on the age of the child (BMWFJ, 2011a).

1.3 Situating the daily life of women within the Austrian system

To further illustrate the need for research that starts in the everyday lives of women as it is situated within and coordinated to the particularities of the Austrian context, I am reflecting in the following paragraphs more specifically on the situation of women within the Austrian system. The Austrian welfare state regime, that is the interaction of the family, the market, and the state in the distribution of social welfare (Esping-Andersen,

1990) has been described as aligning with a conservative model. This type of welfare state regime is characterized by a high level of social stratification (Arts & Gelissen, 2002; Esping-Andersen, 1990), whereby gender can be seen as one basis for social stratification (Bambra, 2007). In Austria social status and related differentials are primarily generated through enrollment in paid employment and the assignment to insurance institutes based on profession or professional status, that leaves individuals with no choice (Ivansits & Pfeil, 2010). Also gender serves as a means for social stratification given the role of Austrian women in the labor market and their assignment as informal care givers.

The strong reliance on the traditional family in Austria has grown historically and exemplifies an ideology which was perpetuated over time (Weiss, 2010). Since the 18th century the traditional family is thought of as a married couple and their children in Austria: the mother is responsible for the reproductive work in the private sphere, whereas the father performs productive work in the public arena (Weiss, 2010). The traditional family was further strengthened by the salient role of the Roman Catholic Church (Knittler, 2010). Based on an analysis of public laws related to family matters, including acts on child and elderly care, Austria reveals an explicit familialism. Explicit familialism is characterized by generous models for maternity leave and only limited public child care for children under three years; as well as care allowances paid to elderly persons that can be used for compensating family members for their care provision (Leitner, 2003). Such generous models may lead to a discouraging situation for women in the labor market. Furthermore, as described earlier in this chapter, pregnant women are required to take a protected leave from paid employment eight weeks before a child's birth which restricts options within the particular time period for reconciling employment and motherhood.

The first decade of the 21st century was characterized by a center-right government in Austria that has further reinforced the traditional family; the government offered "generous transfer payments and long leave periods, thus providing strong incentives for women to exit the labor market" (Obinger et al., 2010, p. 61). Public daycare and incentives for fathers to take paternity leave remained scarce (den Dulk & van Doorne-

Huiskes, 2007). Such family and work policies left women still with the main responsibility for caregiving and housework and strengthen the traditional family model even further (Sauer, 2007). In 2007, a Coalition Government was built by Social Democrats and Christian Democrats. This Coalition modified benefits implemented by the center-right government, and introduced earning-related childcare allowance along with other options for child care allowance outlined earlier in this chapter, and a cost-free and compulsory kindergarten year for children aged 5 years prior to entering primary school. These initiatives were geared toward providing families with more choices and supporting women in reconciling family and employment (Obinger et al., 2010). While women are shifting increasingly from full-time homemaker to the dual role of homemaker and earner, societal and institutional practices only adopt slowly to these changing patterns (Esping-Andersen, 2009; Giele & Holst, 2004; Notz, 2010).

Several scholars have stressed that gender expectations are changing in Western society (Esping-Andersen, 2009; Giele & Holst, 2004; Moen, 2003). In a 2010 report on the position of Austrian women in the labor market (Bergman, Papouschek, Sorger, & Schönauer), almost half of the women indicated that they had reduced their working hours for reasons of informal care in comparison to three percent of men in Austria who indicated further education as the main reason for reduced working hours. Furthermore, women are most likely to take on part-time jobs at the peak of their careers while men tend to do so more in the early or late stages of their careers (Bergman et al., 2010). Part-time employment becomes thus a rather typical form of employment for women (Knittler, 2010; Notz, 2010). If women are co-insured and stay at home as informal caregivers and housekeepers or work part-time below the minimum threshold that does not link them to the mandatory insurance scheme, the insurance status of these women may have implications for women's eligibility to certain social benefits and services (Knittler, 2010). For instance, eligibility for unemployment and invalidity benefits is dependent on the proof a certain period of previous insurance periods.

Hence, how mothers with rheumatoid arthritis are going about their daily lives, including participation in paid employment, may not only be influenced by their personal preferences and choices, and the biomedical characteristics of rheumatoid arthritis, but

also by their situatedness within the Austrian system. Being situated in this context may open up varying resources and possibilities for what women can do and actually do. Consequently considering the situatedness of women within their social context is important to comprehensively understand what they do in the actualities of their daily lives. Given the strong emphasis on the traditional family model in Austria, becoming a mother, and taking on the primary role as informal caregiver, is highly valued within the social context. Thus, the focus of my dissertation is on Austrian mothers of employable age. More specifically, the focus is on Austrian women, who are managing employment, motherhood, and rheumatoid arthritis in the actualities of their daily lives, and how such management is situated within their contexts.

1.4 Situating this dissertation in occupational science

Occupational science is concerned with the study of human occupation, whereby human occupation is understood as “the various everyday activities people do as individuals, in families and with communities to occupy time and bring meaning and purpose to life. Occupations include things people need to, want to and are expected to do” (ISOS, 2011). In Austria occupational science is only slowly emerging with no corresponding university program in place at this point (Prodingler & Stamm, 2011). My understanding of occupational science as an international and interdisciplinary field of study (Laliberte Rudman et al., 2008) is strongly informed by my studies at The University of Western Ontario. While occupational science has emerged out of the profession of occupational therapy, it is important for occupational science

“to shift the discussion away from the basic and applied dichotomy towards a socially responsible focus that necessitates a blurring of traditional basic and applied boundaries coupled with political, ethical and moral considerations associated with knowledge generation to action” (Laliberte Rudman et al., 2008, p. 140).

Noteworthy, such knowledge generation is not tied to the profession of occupational therapy, but occurs in reciprocity with various disciplines including occupational therapy.

As occupational science is an emerging discipline, even more so in Austria than in Canada, I outline my understanding of occupational science as an interdisciplinary and

international discipline committed to understanding human occupation as it occurs within the social context. I address in particular current critiques about the emphasis on meaning and purpose related to occupation, outline approaches that have been suggested for studying the situated nature of human occupation, and clarify how I envision my research to be situated in and contributing to occupational science.

The discipline of occupational science – current critiques from inside the discipline

Occupational science is rooted in the profession of occupational therapy. For instance, values and traditions that have characterized the profession of occupational therapy have been carried forward in occupational science (Kantartzis & Molineux, 2012); occupational science has been often situated within university structures in close relation to occupational therapy (Frank, 2011; Prodingler & Stamm, 2011); and one of the aims assigned to occupational science was the provision of a more rigorous foundation for occupational therapy (Magalhães, 2012). Values and traditions grounded in occupational therapy and carried forward in occupational science refer to the prevailing individualistic perspectives in knowledge generation within occupational science (e.g. Dickie, Cutchin, & Humphry, 2006; Hocking, 2009; Hocking, 2012; Laliberte Rudman, 2012; Magalhães, 2012), as well as the reference to meaning and purposeful occupations (e.g. Kantartzis & Molineux, 2012), and the categorization of occupations into productivity, leisure, and rest or self-care (e.g. Hammell, 2009; Jonsson, 2008). Individualistic perspectives have been taken on despite the acknowledgment that context is significant for understanding human occupation as becomes evident for instance in the definition of occupation by ISOS and its reference to occupations in which people engage in their families or communities, as well as the engagement in occupations that individuals are expected to do (ISOS, 2011). Various researchers have critiqued the predominance of a Western worldview in the knowledge generation about human occupation (e.g. Hammell, 2009; Kantartzis & Molineux, 2011, 2012; Magalhães, 2012; Molke, 2009). Further research has been called upon by occupational scientists referenced above, that generates knowledge about the occupations of individuals as situated within the social and political context. I position my dissertation research as a response to this call for further research in occupational science about the situated nature of human occupation.

It is the aim of this section to briefly outline some of the social, historical, and disciplinary developments that have shaped and informed the emphases on an individualistic perspective, on meaning and purpose related to occupation, and the categorization of occupation into productivity, leisure, and rest or self-care. Subsequently, I outline why I believe taking on an individualistic perspective to understand human occupation falls short in understanding the situated nature of what individuals do. This research builds upon this argument and aims to further the understanding of how Austrian women with rheumatoid arthritis go about their everyday lives given the social context in which they find themselves in. Thus, it is argued that engagement in various activities throughout their daily lives is not only influenced by individual preferences and choices, but also by the varying resources and possibilities that open up given their situatedness within the social context.

Challenging normative assumptions regarding what people do in their daily lives in occupational science

Occupation, as used by occupational scientists, refers most frequently to particular activities or doings, namely those that are assigned with a particular meaning and purpose (ISOS, 2011; Kantartzis & Molineux, 2012). Assigning meaningful and purposeful occupations to the categories of productivity, leisure, and self-care has become the dominant way for occupational scientists to systematize occupations in Western culture (Jonsson, 2008). The categorization of occupations into productivity, leisure, and self-care bears implicit assumptions on how an individual should spend her time. Wilcock et al. (1997) have argued that obtaining and maintaining an 'ideal' balance across occupations contributes to health. Normative ideals point to how an individual should live life (Morgan, 2010). In occupational science, implicit normative assumptions have been increasingly challenged and put under scrutiny as I outline in the subsequent paragraphs.

For occupation to be health promoting, the occupational science and therapy literature often proposes that engagement in occupations should be personally fulfilling, allow for self-expression, and as such, bear meaning. Hence, meaning is described as a positive

term. However, the positivity assigned to occupation should not be assumed to be universally applicable (Hammell, 2009). Kantartzis and Molineux (2012) argued that meaning as conceptualized in occupational science reflects a turn against materialism in the Western world. They argue that Western institutions, such as Christianity and the industrial revolution, influenced and shaped significantly the occupations in which people engage, as well as the values and beliefs attached to these occupations. For instance a hard work ethic was promoted by Christianity. Such work ethic implied that hard work was perceived as significant in the daily life of individuals. Work that was not valued in economic terms, such as housework or informal caregiving, became invisible and not as much valued as paid work (Kantartzis & Molineux, 2012). The engagement in meaningful occupations is then not considered based on its economic value but rather based on its personal meaning, and thus described as a turn against materialism.

Throughout the industrial revolution work became further regulated. This development brought about the divide of work, leisure, and self-care. The daily lives of families became ordered in line with this division (Kantartzis & Molineux, 2012). The categorization in three sub-categories (productivity, leisure, and self-care) is dominant particularly in the context of North-American and European occupational therapy practice. This division was also taken up in occupational therapy and carried forward in occupational science (Jonsson, 2008). The work ethic promoted by Christianity, as well as the industrial revolution implied that people should be active. In particular hard work was perceived as most valuable (Kantartzis & Molineux, 2012).

The historical developments influenced by Christianity and the industrial revolution, exemplifies that social context shapes which occupations individuals would come to value. Persson, Erlandsson, Eklund, and Iwarsson (2001) have outlined that the dimension of value is integral to the understanding of meaning. Value is described in terms of concrete value (e.g. skills, capacities, and/ or product that results out of an occupation), symbolic value which points to the personal and cultural significance of an occupation, and self-reward value underscoring the enjoyment through the engagement in occupations. In particular symbolic value directs attention to the significance or purpose that an occupation serves. The purpose, however, may not only serve individual interests

and preferences, but may also be influenced by religions, social, cultural, and political factors (Kantartzis & Molineux, 2012), or individuals may choose to engage in occupations that are congruent with their own values and beliefs as well as with those of their communities (Galvaan, 2012). Individuals may engage in occupations that become shaped and promoted as ideal, adequate and normal within the context in which they find themselves (Laliberte Rudman, 2005; 2010).

Taking the social context into consideration in generating knowledge about occupation

Given this interrelation and interaction between the occupations in which individuals engage, and the social context, I agree with other occupational scientists (e.g. Dickie et al., 2006; Hocking, 2012; Laliberte Rudman, 2012; Magalhães, 2012) that an individualistic perspective in generating knowledge about human occupations falls short in understanding the situated nature of what individuals do in their daily lives. Different approaches toward knowledge generation have been suggested by occupational scientists, such as transactionalism (e.g. Cutchin & Dickie, 2012; Dickie et al., 2006), or a governmentality perspective (e.g. Laliberte Rudman, 2010; 2012). In the remainder of this chapter I briefly outline these two perspectives. I conclude this chapter with the argument that these perspectives have made valuable contributions to occupational science, however, what is still lacking is an approach that allows for knowledge generation that starts at the actualities of everyday life and explores from there how these actualities become accomplished and shaped through the social context.

Dickie et al. (2006) suggested a transactional perspective for the study of human occupation that draws upon Dewey's action theory. Using a transactional perspective inherently moves away from an individualized toward a contextualized perspective as any occupation is a transaction co-constituted by the person and the context (Cutchin & Dickie, 2012; Dickie et al., 2006). As explicated by Aldrich (2008), "[t]ransactionalism posits that the character of elements is contingent, changing according to the composition and configuration of other elements in every situation" (p. 151). The transaction between the person and the environment is ever-present as we as individuals inhabit the world we

live in (Shank & Cutchin, 2010). Transactionalism acknowledges a contextualized rather than individualized perspective on people's occupations.

Drawing upon a governmentality perspective, Laliberte Rudman (2010; 2012) highlighted that the celebration of the ideal, good, and healthy way in occupational science, as well as within broader societal institutions, may marginalize those who are not able to live up to these norms given their resources. In calling for research that addresses the situated nature of what people do in their daily lives, Laliberte Rudman (2010) calls for research that is critically reflexive upon ways of conceptualizing occupations that may marginalize the engagement of some people or groups of people. For example, in relation to women with rheumatoid arthritis, such research would put under scrutiny if becoming a mother is conceptualized as ideal within the Austrian context, and engagement in paid employment is highly valued when being of employable age. Subsequently, such investigation would open up whether women with rheumatoid arthritis who may experience challenges in living up to this ideal may be rendered marginal.

These two perspectives exemplify current efforts toward furthering the knowledge about the situated nature of occupation. Each perspective adds a distinct dimension: From my perspective, in transactionalism the starting point rests more on the individual that is in constant inter- and transaction with the social context. A governmentality perspective opens up further understanding of how daily life is shaped by relations of power, and allows for understanding how macro-level elements create norms about how an individual should go about daily life. My argument is that while these perspectives have made valuable contributions to occupational science, what is still lacking is an approach that allows for knowledge generation that starts at the actualities of everyday life and explores how these actualities are coordinated to and at the same time become accomplished and shaped through the social context. Thus, I aim with this research to contribute to the understanding of the situated nature of what individuals actually do in their daily lives.

Chapter 2

2 Daily life of women with rheumatoid arthritis

The purpose of this chapter is to provide a review of medical and rehabilitation literature that informs the current knowledge base about the daily lives of women with rheumatoid arthritis. This literature review was informed by the disjuncture at which my dissertation research started and aimed to further understand the current knowledge base about how women manage the impacts of the disease in their daily lives and how current arthritis-related treatment approaches respond to their needs in their daily lives. I begin this chapter with a short overview on the medical condition of rheumatoid arthritis which dominated my understanding of rheumatoid arthritis when I was working in clinical practice. Then, I review research that has attempted to address women's daily lives and how the complexity of their daily lives is addressed in arthritis-related treatment and health care. Given the explicit familialism and strong emphasis on employment within the Austrian context, I reviewed literature in particular on mothering and participation in paid employment in women with rheumatoid arthritis. This chapter concludes with a discussion on how this body of literature is characterized by an individualized perspective and focus on medical condition and disease-related symptoms that may impact on various domains of life. I argue based on my clinical experience and on the review of this literature that such knowledge is limited in providing an understanding of how women actually go about their daily lives and manage the actualities of their daily life as it is coordinated to the social context that entails organizational processes in health care and beyond.

2.1 The medical condition of rheumatoid arthritis

Rheumatoid arthritis is a systemic autoimmune disease that involves inflammation of joints, especially the small joints of hands and feet, but also wrists, elbows, shoulders, and knees. Pain in and around joints, stiffness, and fatigue are common symptoms (O'Brien & Backman, 2010). The prevalence of rheumatoid arthritis varies between 0.3% and 1% in the industrialized world (WHO, 2003). In people below the age of 50, the

incidence of rheumatoid arthritis is 4-5 times higher in women than in men, whereas this ratio changes to 2:1 above the age of 60 (Kvien, Uhlig, Ødegard, & Heiberg, 2006). Criteria for classifying rheumatoid arthritis contain the involvement of joints (at least two large or one or more small joints); evidence for a positive rheumatoid factor or positive anti-citrullinated protein antibody in serology; acute-phase reactants (may include abnormality of the C-reactive protein or erythrocyte sedimentation rate); and a duration of symptoms for at least six weeks (Aletaha et al., 2010).

Over the past couple of decades significant advances have been made in the understanding of pathophysiological mechanisms, diagnostic algorithms, and therapeutic approaches related to rheumatoid arthritis (Busse, Blümel, Scheller-Kreinsen, & Zentner, 2010; Kavanaugh, 2010; Machold, Nell, Stamm, Aletaha, & Smolen, 2006; Villeneuve & Emery, 2009). The etiology of rheumatoid arthritis is not clear yet; “the interaction of different environmental factors in genetically predisposed individuals is likely what triggers the disease” (Tayar & Suarez-Almazor, 2010, p. 202). Rheumatoid arthritis is a non-curable disease, where the aim of treatment is remission or if remission is not achievable then the aim is achieving and sustaining low disease activity (Smolen, Aletaha, et al., 2010). Remission is “a state with no apparent disease activity and absence of joint damage and disability progression” (Villeneuve & Emery, 2009, p. 110). Regular follow-ups with the rheumatologist are recommended to assess disease activity and adjust treatment if needed: more specifically, patients with active disease activity are recommended to see their rheumatologist every 1-3 months; later on every 3-6 months (Smolen, Aletaha, et al., 2010). Furthermore, annual radiographs of hands and feet are recommended to evaluate for radiographic changes in the joints (Villeneuve & Emery, 2009). In terms of treatment, “the mainstay of RA treatment is the application of DMARDs” (disease-modifying anti-rheumatic drugs; Smolen, Landewé, et al., 2010, p. 964). It is recommended that treatment with DMARDs is initiated once diagnosis of rheumatoid arthritis is established (Smolen, Landewé, et al. 2010).

Individuals with rheumatoid arthritis indicated that they receive a release from medication, such as biological DMARDs (Lindén & Björklund, 2010), and are enabled to re-engage and participate in daily life (Lindén & Björklund, 2010; Nilsson, Fitinghoff, &

Lilja, 2007). Nevertheless, symptoms such as pain and fatigue remain present though in a lower intensity and individuals with rheumatoid arthritis may experience a certain level of anxiety as they are unsure about the long-term effect of medications as well as side-effects of medications (Nilsson et al., 2007; Van der Meer et al., 2011). Fear due to the long-term consequences of rheumatoid arthritis, uncertainty about the future, and yet hope that arises out of the belief in medical research are salient experiences of people living with rheumatoid arthritis (Lütze & Archenholtz, 2007). A study revealed that very little is actually known about patients' perspectives on remission (van Tuyl et al., 2011).

Most of the literature reviewed in this section was conducted with a reference to gender as socio-demographic characteristic, rather than as a lived reality. For instance authors of these studies included more women than men in their study sample and justified their sampling strategy by the higher prevalence of rheumatoid arthritis in women than in men: Nilsson et al. (2007) had a study sample of six women and four men, Van der Meer et al. (2011) sampled twelve women and two men, or Lütze and Archenholtz (2007) recruited 17 women and six men. In some studies authors pointed to gender differences based on their findings that would require further attention in research and rehabilitation. This consideration of gender as mainly a socio-demographic factor is applied to enhance generalizability of research findings as the gender distribution in the sample is considered as representative of the overall group of people with rheumatoid arthritis.

This short synopsis of literature about the medical condition of rheumatoid arthritis that informs clinical practice is characterized by a focus on the medical condition and disease-related symptoms. Knowledge generation is geared toward establishing facts and establishes objectifiable, measurable and observable markers to predict and control the further course of the disease. Such knowledge generation is limited in attending to the voice of individuals experiencing and living with rheumatoid arthritis; attending to the voice of individuals might be actually seen as a threat to objectivity (Lincoln, Lynham, & Guba, 2011). Some research has been conducted though that attended to the lived experiences of individuals with rheumatoid arthritis, such as the study by Lindén and Björklund (2010), Nilsson et al. (2007), or Lütze and Archenholtz (2007). Nevertheless, when it comes to the development of diagnostic and treatment algorithms, such

knowledge appears to be subordinated to knowledge that allows for prediction, control, and objectivity. Subsequently, the lived experiences of individuals with rheumatoid arthritis may be rendered marginal in clinical practice. In the next paragraphs I focus specifically on the current knowledge base on how women with rheumatoid arthritis manage their daily lives. In contrast to the literature reviewed in this section, the literature in the next section does not focus on the medical condition of rheumatoid arthritis and related treatment, but rather on what is known about how women with rheumatoid arthritis are going about their daily lives.

2.2 The complexity of the daily life of women with rheumatoid arthritis

Given the chronic nature of rheumatoid arthritis, research has been dedicated to further understand how women, and particularly mothers with rheumatoid arthritis adapt to and change their engagement in daily life throughout the course of their disease (Dubouloz, Vallerand, Laporte, Ashe, & Hall, 2008; Stamm et al., 2008; Stamm, Machold, Smolen, & Proding, 2010). This recent body of literature underscores persisting functional limitations in the lives of women with rheumatoid arthritis (Bjork, Gerdle, Thyberg, & Peolsson, 2008; Bjork, Thyberg, Skogh, & Gerdle, 2007; Thyberg, Hass, Nordenskiold, Gerdle, & Skogh, 2005). Moreover, the allocation of time to engage in particular activities and occupations changes over the course of the disease (Forhan & Backman, 2010; Katz & Morris, 2007; Reinseth & Espnes, 2007; Stamm et al., 2009; Wikström & Jacobsson, 2005). Women with rheumatoid arthritis negotiate and prioritize continuously what they are doing in their daily lives based on what is important for them and brings meaning (Alsaker & Josephsson, 2003; Alsaker & Josephsson, 2011; Stamm et al., 2009). Furthermore, women also negotiate the engagement in social roles (Plach, Stevens, & Moss, 2004; Plach, Napholz, & Kelber, 2005) such as being a mother (Backman, Del Fabro Smith, Smith, Montie, & Suto, 2007; Barlow, Cullen, Foster, Harrison, & Wade, 1999; Del Fabro Smith, Suto, Chalmers, & Backman, 2011; Grant, 2001; Katz, Pasch, & Wong, 2003) or being an employee (Nilsson et al., 2007). While maintaining paid employment is a challenge for women with rheumatoid arthritis (Backman, 2004; Kessler et al., 2008; Li, Gignac, & Anis, 2006; Nilsson et al., 2007; Reisine, Fifield, Walsh, &

Feinn, 2001; Shanahan, Smith, Roberts-Thomson, Esterman, & Ahern, 2008; Verstappen et al., 2004), paid employment has been described as being an unmet need in health care (Lacaille, White, Backman, & Gignac, 2007; Van der Meer et al., 2011).

The literature reviewed in this section was partly conducted specifically about women. As consideration of gender as a lived reality rather than socio-demographic characteristic has only received increasing recognition over the past several years, I included literature relevant to the understanding of how individuals with rheumatoid arthritis manage their daily lives that did not focus specifically on women. This recognition of gender as a lived reality is influenced by an increasing understanding that disease activity based on medical markers alone is not sufficient to understand disease activity as experienced by the individual living with the disease (e.g. Reisine et al., 2001; Wikström & Jacobsson, 2005). Furthermore, there is increasing understanding that the advanced and more specific treatments allow individuals with rheumatoid arthritis to live a life without severe pain and continuous joint deformities (e.g. Busse et al., 2010; Lindén & Björklund, 2010; Villeneuve & Emery, 2009); and yet, rheumatoid arthritis is a chronic disease that has to be continuously managed and negotiated in daily life (e.g. Alsaker & Josephsson, 2003; Forhan & Backman, 2010; Katz & Morris, 2007; Stamm et al., 2008). Thus, my interest in the following sections was particularly on the current knowledge base regarding processes of managing rheumatoid arthritis, which entails managing the disease, and engagement in daily occupations such as mothering and participation in paid employment. I focused on mothering and paid employment specifically, as these are likely to be significant occupations for an Austrian woman of childbearing and employable age given the social context of Austria in which social policies rest on the traditional family model of the female caregiver and homemaker and social insurance system build upon individuals' employment status (see Chapter 1).

Processes of adaptation

Given the chronic nature of rheumatoid arthritis, women with rheumatoid arthritis have to continuously adapt to and change their engagement in daily life throughout the course of their disease (Dubouloz et al., 2008; Stamm et al., 2008; Stamm et al., 2010). Such

adaptation processes have been described as being progressive and complex (Dubouloz et al., 2008), or as processes of mastering or getting used to rheumatoid arthritis (Stamm et al., 2008). Progressive adaptation occurs continuously as symptoms are persistent, whereas complex adaptation is triggered by an acute episode. These processes are influenced by factors such as the fluctuating and invisible nature of the disease, the sense of having control and hope for remission instilled by medication, and the onset of the disease at times when family planning and career development are important considerations for individuals (Dubouloz et al., 2008). In a narrative study conducted with women and men with rheumatoid arthritis in Austria, it was found that the process of adapting to the disease is much more than just adapting and included processes of integrating rheumatoid arthritis in a personally meaningful way; for some individuals living with rheumatoid arthritis meant making “the best of a bad situation” (Stamm et al., 2008, p. 664). A secondary analysis of these narratives stressed the importance of the social context to comprehensively understand the lived reality of individuals (Stamm et al., 2010): factors such as accessibility to and content of health care services, the support provided by family, and negotiations of social and cultural values such as taking up paid employment when being of employable age circumscribed and shaped the process of adapting and adjusting to the disease (Stamm et al., 2010). These findings emphasize the continuous and subjective processes that living with rheumatoid arthritis entail and how processes of adapting to the disease occur between the individual and her social context.

The continuous process of adapting to and living with rheumatoid arthritis has also been described in terms of persisting limitations that women with rheumatoid arthritis experience throughout their lives (Bjork et al., 2008; Bjork et al., 2007; Thyberg et al., 2005), and how these persisting limitations may impact their time spent in certain occupations (Katz & Morris, 2007; Reinseth & Espnes, 2007; Wikström & Jacobsson, 2005). Findings from a Swedish cohort study demonstrated that even after five years of disease onset individuals with rheumatoid arthritis experience persisting limitations (Bjork et al., 2008; Bjork et al., 2007). After three years of disease onset, women experienced more difficulties in their upper extremities and in their activities than men. These findings led the authors to conclude that the course of the disease is more severe in women than in men (Thyberg et al., 2005). Time use patterns of women with rheumatoid

arthritis may change as their functional status changes (Katz & Morris, 2007; Reinseth & Espnes, 2007; Wikström & Jacobsson, 2005). In a study conducted with women and men with rheumatoid arthritis in the US, it was found that increased disease severity meant that individuals spend more time with personal care, resting and sleeping and less time caring for family, paid work, leisure activities, meeting with friends or volunteer work (Katz & Morris, 2007). A cohort study by Wikström and Jacobsson (2005) revealed that changes in time-use cannot be simply explained by disease activity or medication-intake. The authors suggest that factors such as participation in rehabilitation programs, personal coping strategies, and the social environment might be influential. In the study conducted by Reinseth and Espnes (2007) specifically with women with rheumatoid arthritis, women reported a decrease in non-vocational activities, which include leisure and household activities, over the past ten years; not only did physical functioning reveal as having an impact on the participation in these activities, but to an even greater extent mental health. These studies illustrate that women may experience changes in their activities as they live with the disease; factors beyond characteristics of rheumatoid arthritis occurred influential.

Engaging in meaningful occupations

Research has also been conducted to investigate specifically the engagement of women with rheumatoid arthritis in occupations that are meaningful to them. Alsaker and Josephsson (2003) illustrated how individuals with chronic rheumatic diseases such as rheumatoid arthritis continuously change and adapt their occupations while negotiating the meanings attached to their doings. These meanings are anchored in their biographies, and “meaning may be imbued in everyday occupations, and thereby serves as a mediator of values in their everyday lives” (Alsaker & Josephsson, 2003, p. 171). For instance, one participant in the study of Alsaker and Josephsson (2003) was mentioning how a particular lunch has to be prepared, whereby the how-to-do was passed on over generations; despite the increased challenges and discomfort given the disease, the participant continued doing it with slight modifications. People with chronic rheumatic diseases are also engaging in moral quests about whether they do well enough and can ensure being a good citizen also in the future (Alsaker & Josephsson, 2011).

Balancing what is meaningful and important for oneself and what is considered as such within the socio-cultural context is also a dimension that was found to be important in reference to occupational balance in people with rheumatoid arthritis (Stamm et al., 2009). Forhan and Backman (2010) described, based on a linear regression model, three dimensions that explain occupational balance in people with rheumatoid arthritis: “ability to perform main occupation (...), satisfaction with the balance of time spent on occupations (...), satisfaction with the day’s accomplishments” (Forhan & Backman, 2010, p. 134). Participants reported mainly paid work or unpaid work (housework, caregiving) as their main occupations. Though about a third of participants reported limitations in these occupations, these limitations did not impact on the findings related to the dimension of satisfaction with balance. These insights illustrate that the impact of the disease on the functioning of women with rheumatoid arthritis is only one part of a complex whole. Individuals with rheumatoid arthritis negotiate and prioritize continuously what is meaningful for them and important within the socio-cultural context.

Managing engagement in occupations of daily life entails negotiating support from family or friends. Support has been described as either collaborative or constructive as long as it occurs ‘naturally’ (Nyman & Larsson Lund, 2007). ‘Natural’ implies that the individual still has control over the occupation, and the person providing the support understands the individual with her abilities and difficulties, and the significance of a particular occupation. Inadequate support was perceived as a source of frustration by women with rheumatoid arthritis (Goodacre & Goodacre, 2003). For mothers with rheumatoid arthritis, being offered and accepting support was more challenging when family members were strongly relying on traditional gender roles (Grant, 2001). While women with rheumatoid arthritis in midlife described a better functional status and fewer co-morbid health problems than older women with rheumatoid arthritis, they experienced less role balance, many concurrent role obligations, and responsibilities in their midlives that dictate everyday life (Plach et al., 2004). The social roles that women referred to included being a spouse or partner, mother, homemaker, and employee. Such examples from the literature exemplify that social context matters not only in regard to what women do in their daily lives, what brings meaning to their lives, and is important within

their context, but also how women relate to and interconnect with others. Participating in mothering and employment directs attention to how the daily lives of women with rheumatoid arthritis occur in constant and continuous interaction with other people and become part of daily life.

Being a mother and an employee is something that might be highly valued within a given social context such as Austria that builds on the premises of the traditional family within a social insurance based welfare state (see Chapter 1). Within the scope of the next paragraphs I drew upon literature published internationally on mothering and paid employment in women with rheumatoid arthritis to gain a more comprehensive understanding about current knowledge generation on mothers with rheumatoid arthritis, as well as women of employable age with rheumatoid arthritis in a broader context before focusing in my research particularly on the Austrian context.

Mothering

In an mixed method study, that included a cross-sectional survey method and focus group discussions, mothers with rheumatoid arthritis described the challenges in keeping up with a very active and lively young child, and also the challenges in keeping up with increased volumes of laundry, groceries, and meal preparation as the children grow older (Barlow et al., 1999). Almost half of the women with rheumatoid arthritis who participated in a US-panel study reported difficulties in performing parenting activities regardless of the age of children (Katz et al., 2003). Backman, Del Fabro Smith, et al. (2007) referred to these challenges as a continuum between “sometimes I can” to “sometimes I can’t” (p. 383). This continuum illustrates how the ability to participate in mothering fluctuates over time given daily fluctuations and the overall progression of the disease, as well as the changing demands in mothering. Once children are older they may need rides to various activities, or parents are asked to volunteer for various things, which can pose a challenge too (Backman, Smith, Smith, Montie, & Suto, 2007; Del Fabro Smith et al., 2011).

In a narrative study by Del Fabro Smith et al. (2011) women explained that being a mother meant for them orchestrating daily life: plan ahead, balance the increased need of

rest, ask for help such as arrange somebody to pick the children up from school, adjust occupations which may constrain other occupations, re-schedule participation in certain things if necessary, and be present as an active observer. Fatigue was described as a factor that made things particularly complicated. Women across several studies referred to feeling inadequate in fulfilling their role as a mother (Backman, Smith, et al., 2007; Barlow et al., 1999; Grant, 2001). Similarly, mothers felt challenged when being confronted with expectations based on what a normal mother does and can do (Del Fabro Smith et al., 2011). Such expectations included physical activities with the child, attending outings, and following normal daily routines that entail child care and housework. When having more than one child, mothers also referred to their reliance on the help of the older child, while at the same time feeling guilty about it (Barlow et al., 1999). Despite the challenges inherent in negotiating mothering and rheumatoid arthritis, women described how children motivate them to engage in exercise programs (Barlow et al., 1999), or being a mother is very meaningful part of their identity that they would not like to miss in their lives (Del Fabro Smith et al., 2011). The body of literature on mothers with rheumatoid arthritis has a particular emphasis on the challenges that mothers may experience in mothering due to the limitations and impact of their disease. Only limited attention is given to the significance for women of being a mother within their social context. While mothering has been described as meaningful and motivating for women with rheumatoid arthritis, limited attention has been given to social norms and values that become assigned to mothering within a given social context.

Participating in paid employment

Similar to mothering, people with rheumatoid arthritis also assign personal meaning to employment. In a qualitative study conducted in Sweden, individuals with rheumatoid arthritis valued the challenges involved in their work, enjoyed being together with co-workers, and gained motivation to get better during periods of sick-leave (Nilsson et al., 2007). While maintaining paid employment is often found to be a challenge for women with rheumatoid arthritis (Backman, 2004; Kessler et al., 2008; Li et al., 2006; Nilsson et al., 2007; Reisine et al., 2001; Shanahan et al., 2008; Verstappen et al., 2004), paid

employment provides not only financial security, but also can provide intrinsic satisfaction, self-confidence, and social contacts.

In particular, the issue of disclosure at one's work place regarding one's diagnosis has been found to be a dimension that needs to be negotiated by the individual and that contributes to the complexity of managing the disease and employment (Gignac et al., 2004). Individuals with rheumatoid arthritis who have disclosed their disease at the workplace received more modifications at the workplace (Gignac, 2005), and not disclosing the disease prevented people from further measures that would likely support continuing employment such as workplace adaptation and use of assistive devices (Lacaille et al., 2007). When disclosing the disease, however, interpersonal relations at the work place were described as challenging at times due to resentments of co-workers or lack of understanding in part due to the invisibility of the disease. At the same time, for some individuals with rheumatoid arthritis the conversations with co-workers about their disease can be beneficial to enhance co-workers' understanding of the disease (Nilsson et al., 2007; Van der Meer et al., 2011). Several studies highlight that working conditions, including flexibility of working hours and breaks, having control over how the job is done, and demands of the respective job are important factors in whether or not people are able to maintain employment (Lacaille et al., 2007; Nilsson et al., 2007). Challenges in commuting (e.g. increased fatigue due to long commuting, difficulties in using public transport) are influential factors for people with rheumatoid arthritis in their efforts to continue employment (Lacaille et al., 2007).

These studies exemplify that participating in and maintaining paid employment cannot be comprehensively understood when focusing solely on the individual who is working at her work place. The relations with employer and co-workers, the way to and from work, and regulations about working hours are some factors that constitute resources and/ or barriers and open up varying possibilities for women with rheumatoid arthritis to sustain paid employment.

The literature presented in this review on mothering and participation in paid employment, for the most part, takes the social context for granted. For instance, the

discussion is whether individuals disclose their disease and how it impacts their access to accommodations and adaptations at the work-place. The focus remains on the individual, and how she negotiates daily life as it occurs within a social context that is co-constituted by activities of various people, structures, and processes. Despite that participation in social roles revealed as crucial in understanding women's daily lives, the social roles that an individual with rheumatoid arthritis inhabits, such as being an employee, revealed as an unmet need in health care (Lacaille et al., 2007; Van der Meer et al., 2011).

2.3 Women with rheumatoid arthritis and arthritis-related health care

The knowledge base presented so far focuses predominantly on the disease and the individual. The impact of rheumatoid arthritis in women's daily lives is addressed and becomes presented primarily as a problem of the individual with a medical condition. However, daily life is complex and occurs within a social context. The body of knowledge presented so far aligns to some extent with the disjuncture that I experienced in clinical practice: the emphasis in the literature is predominantly on the individual and the characteristics and impact of rheumatoid arthritis in light of medical parameters and functional limitations. Literature on how women with rheumatoid arthritis manage the complexity of daily life, where managing the disease might be part of a complex whole, is marginal. In this section I focus more specifically on recent developments, namely the implementation of self-management and educational programs in arthritis-related health care, to gain more insights on current efforts in rehabilitation practice toward integrating characteristics about rheumatoid arthritis, the individual living with the disease, and daily life. Moreover, I review literature that addresses the perspectives of patients and health professionals on arthritis-related health care.

Self-management and educational programs

To address the continuous changes and processes of adaptation of women with rheumatoid arthritis, self-management or educational programs are increasingly implemented in arthritis-related health care practice (Albano, Giraudet-Le Quintrec, Crozet, & d'Ivernois, 2010; Bruce, Lorig, & Laurent, 2007; Hannes, Hauge, Kjekken, &

Hagen, 2011; Iversen, Hammond, & Betteridge, 2010). Such programs aim to empower individuals so that they take on responsibility for their own health. Next to the body of literature on empowering individuals with rheumatoid arthritis toward taking on responsibility for the impact of the disease on their daily life, an increasing body of knowledge has been generated about the experiences and perceptions of women with rheumatoid arthritis and the health-care provided to them (Kjeken et al., 2006; Meesters, de Boer, van den Berg, Fiocco, & Vliet Vlieland, 2011; van Hulst, Kievit, van Bommel, van Riel, & Fraenkel, 2011). This latter body of knowledge does not specifically address the disjuncture between the complexity of women's lives and arthritis-related health care, but it provides insights into how the needs of women with rheumatoid arthritis are met in arthritis-related health care. After reviewing literature on self-management programs, and perspectives on arthritis-related health care, I reflect briefly on how the needs of patients with rheumatoid arthritis are addressed or met in arthritis-related health care based on current literature.

Knowledge generated to further understand and advance self-management or educational programs is geared toward an individual with a health condition that requires treatment to manage the health condition, and needs to be empowered to be enabled to take on responsibility for one's own health. Self-management interventions "include educational, behavioral and cognitive approaches to influencing health knowledge, attitudes, beliefs and behaviors to promote independence, maintain or adjust life roles, and address the psychological impact of disease" (Iversen et al., 2010, p. 955). In the literature, self-management programs are frequently presented as part of patient-education programs. A literature review about patient-education programs supports the findings from Iversen et al. (2010) and underscores that such programs aim to enable people to competently manage their disease in daily life or focus on teaching individuals with rheumatoid arthritis strategies so that they have improved skills for coping with the disease (Albano et al., 2010). A qualitative study about the expectations of individuals with rheumatoid arthritis revealed that individuals who participate in self-management and educational programs hope to become empowered to take over more responsibility for the impact of the disease in daily life, to accept and cope with the disease, as well as learn about strategies and information on maintaining employment (Hamnes et al., 2011).

While self-management and education programs appear coherent in their aims and the expectations of individuals participating in such programs, research has pointed out that they are attended more often by groups with particular socio-demographic characteristics such as being white and female (Bruce et al., 2007). The literature on self-management and educational programs stresses the focus on empowering individuals with rheumatoid arthritis, and thus, in a sense also implies a shift of responsibility for the impact of rheumatoid arthritis in daily life to the individuals. However, many dimensions addressed within such programs, such as coping with disease and maintaining employment, have to be negotiated by the individual within the everyday life as it occurs in interaction with other people, as well as broader systems and institutions. These insights point back to the importance of considering the social context in which individuals go about their lives. This context opens up varying resources and possibilities for what women with rheumatoid arthritis can do and actually do depending on their situatedness within the social context.

The disjuncture between arthritis-related health care and everyday life

In my review of literature on how arthritis-related health care attends to the needs of women with rheumatoid arthritis the disjuncture that I experienced in clinical practice was reflected to some extent as well. More specifically, the focus in the literature is on the individual with the medical condition, which falls short in understanding how women with rheumatoid arthritis are actually going about their daily lives.

A very recent body of literature points to divergent perspectives of patients and health professionals on arthritis-related health care. Van Hulst et al. (2011) conducted a survey with patients and rheumatologists to identify factors that are important in the care or treatment process; within their study, both types of participants ranked a list of 58 factors. Only physical functioning and mobility and the rheumatologist's impression of the overall disease activity were ranked by patients and health professionals respectively within the top ten. Beside these two out of 58 factors tremendous differences resulted. Patients' level of comfort in expressing concerns and patient's trust in physicians was ranked high by patients, but not by rheumatologists. Most important for rheumatologists

were the disease activity score and swollen joints, which was not ranked as high by patients (van Hulst et al., 2011). This study illustrates clearly the divergent perspectives of patients and rheumatologists on arthritis-related health care.

Studies on the provision of health care (Kjeken et al., 2006; Meesters et al., 2011) revealed that patients lack information and knowledge about the disease and about health care. Individuals with rheumatoid arthritis stressed that they lack information about content and accessibility to health care services in a cross-sectional study conducted by Meesters et al. (2011). Kjeken et al. (2006) conducted an analysis from survey data specific to rheumatoid arthritis and ankylosing spondylitis. In their study the need of providing patients continuously with information was stressed as individuals with rheumatoid arthritis continuously face new challenges given the unpredictable and fluctuating course of the disease. Patients who reported high involvement in treatment decisions reported high levels of perceived information, were very satisfied with health care, were younger, and had higher levels of formal education; patients with a worse health status and comorbidities reported more 'unmet health care needs' (Kjeken et al., 2006). These findings illustrate that the social context provides individuals with rheumatoid arthritis with varying resources and possibilities to get involved in their treatment processes and to gain and comprehend information. Such resources and possibilities extend beyond the clinical encounter, and are shaped by the situatedness of individuals within the social context.

2.4 The reduction of the complexity of daily life into individualized accounts

Based on the reviewed literature in this chapter so far, I argue that the dominant approach to knowledge generation about the daily lives of women with rheumatoid arthritis that informs clinical and rehabilitation practices is characterized by an individualized perspective and focus on the medical condition and disease-related symptoms. The individual with a medical condition is represented as being in need of treatment; the context in which mothers with rheumatoid arthritis live their lives and negotiate various demands, resources, and possibilities remains largely unattended. In health care, treatment is provided to reduce and control the symptoms of rheumatoid arthritis. While

it is acknowledged in the literature that living with rheumatoid arthritis is characterized by a continuous process of adapting to the disease, the responsibility for managing and coping with the continuous challenges is transferred to the individual. Self-management and education programs are offered to enable women with rheumatoid arthritis to manage daily life, however, the contextual applicability of the concepts and practices underlying self-management, as well as the resources of the person to successfully apply self-management skills, remains largely unattended.

Going about daily life that may include managing family and participating in employment, occurs within the complexity of daily lives, where various people are active and their activities are coordinated amongst each other. Generating objectifiable and observable parameters about the daily lives of women with rheumatoid arthritis constitutes a reduction of a complex phenomenon into specific concepts and categories. Women with rheumatoid arthritis do not think nor live in medical concepts, linear treatment algorithm or practice guidelines (Kjeken et al., 2006; Meesters et al., 2011; van Hulst et al., 2011). Their daily lives are complex: for instance the changes and challenges in the lives of individuals with rheumatoid arthritis cannot be fully explained by disease status (Wikström & Jacobsson, 2005), or support may be perceived as constructive and collaborative, but also as frustrating (Goodacre & Goodacre, 2003; Nyman & Larsson Lund, 2007). The knowledge generated about the complexity of women's lives has been gained within an interpretive paradigm that embraces (inter-) subjective accounts, focuses on meaning and the individual's experience. Such knowledge does not provide factual, objectifiable accounts and does not allow for predicting the further course of the disease; consequently, it is not necessarily taken into account in clinical practice.

To understand and comprehend the complexity of the daily lives of women with rheumatoid arthritis adequately, I argue that approaches to knowledge generation have to account for how women with rheumatoid arthritis go about their daily life within their social context. More specifically, to further understand the disjuncture between the dominant body of knowledge about rheumatoid arthritis, and the actualities of the daily lives of mothers with rheumatoid arthritis, I advocate for critical reflections on what knowledge informs and rules arthritis-related health care practice. Based on the reviewed

literature, the diversity of resources that is available to mothers with rheumatoid arthritis in the actualities of their daily lives, as well as the organizational processes and structures that restrict and support certain possibilities that in turn shape what women do in their daily lives remain unattended. The disjuncture between the daily lives of mothers with rheumatoid arthritis and arthritis-related health care may occur then as health care systems can be seen as “institutional arrangements that have as their objective the treatment of sickness” (Busfield, 2000, p. 114). Nevertheless,

“much of our health is the result of social determinants – such as housing, education, social capital, our natural environment and the way we construct the built environment around us – that are shaped by policy decisions made completely outside the health care system” (McLaughlin & McLaughlin, 2008, p. 5).

Hence, to comprehensively understand the actualities of women’s lives and how the social context shape what they can do and actually do, I believe that attending to the context in which women with rheumatoid arthritis go about their daily lives is crucial.

Chapter 3

3 Going beyond the *individual* – attending to the *social*

The aim of this chapter is to go beyond the dominant approach to knowledge generation about women with rheumatoid arthritis from an individualistic and disease-oriented perspective as outlined in the previous chapter. In this chapter I elaborate more specifically on the importance of taking the social context, which entails the resources and possibilities that are available for individuals to go about their daily lives, into account when aiming to generate knowledge about how women with rheumatoid arthritis go about their daily lives. Knowledge that takes into account a social rather than individualistic perspective related to rheumatoid arthritis refers mainly to the social impact of the disease. Literature that I have found valuable to further understand the complexity of living everyday life with a chronic disease such as rheumatoid arthritis refers to disease and illness as social constructions and not purely biomedical entities, and literature about the social determinants of health that focuses particularly on the living conditions and living circumstances in which individuals go about their daily lives. The body of knowledge about social determinants of health entails reference to the social gradient prevailing in any society, and critical social transitions in people's lives.

Hence, the structure of this chapter is as follows. First, I elaborate on the literature that describes the social impact of rheumatoid arthritis, and current efforts and practices toward reducing the social impact. Then, I attend to literature that outlines some distinct features of a social perspective that may facilitate the understanding of the daily lives of women with rheumatoid arthritis. This body of knowledge includes literature on social norms and values, and on social determinants of health. Knowledge generated from a social perspective focuses predominantly on society. In essence, such knowledge is distinct from knowledge presented in the previous chapter that has focused predominantly on the individual. Building on the knowledge outlined in the previous chapter and in this chapter, this chapter concludes with the argument that research is needed that addresses the situated nature of occupation. Such research is directed toward understanding the interface between the individual and the social context, and how

individuals manage their daily lives at this interface. Hence, such knowledge generation makes it possible to gain more understanding about the complexity of the lives of Austrian mothers with rheumatoid arthritis as it happens within the social context. I conclude this chapter with my arguments about why research is needed about the situated nature of how Austrian women with rheumatoid arthritis go about their daily lives. Throughout this chapter I refer to examples of work⁸ disability in women with rheumatoid arthritis to illustrate my arguments.

3.1 A social perspective on rheumatoid arthritis

Arthritis-related research that incorporated a social perspective has focused primarily on the social impact of rheumatoid arthritis. The social impact is primarily described in terms of its socio-economic impact, namely the direct and indirect costs for society due to the disease. In this body of literature reference is given frequently to the burden of the disease. Hence, in this section I outline some of the current research that is concerned with the socio-economic impact of rheumatoid arthritis, as well as efforts to tackle the burden of rheumatoid arthritis.

The threat, or impact of rheumatoid arthritis on society, that has been referred to as the burden of the disease (Kvien, 2004) occurs due to morbidity, long-term disability, and related direct and indirect costs (Cooper, 2000; Woolf & Pfleger, 2003). People with musculoskeletal diseases,⁹ including rheumatoid arthritis, constitute a substantial group of people receiving invalidity or disability benefits in various countries, such as Austria (BMASK, 2009a), Norway (Jakobsen, 2009), Sweden (Woolf & Pfleger, 2003), or Australia (Shanahan et al., 2008). From a Canadian perspective, Backman (2004) stated “the burden of work disability from RA is substantial in terms of reduced productivity and lost income at both individual and societal levels” (p. 149). Moreover, indirect costs refer to reduced pay due to job changes (Li et al., 2006) as well as people being not

⁸ When using the term 'work' in this chapter, reference is given to paid work.

⁹ 'Musculoskeletal disease' is an umbrella-term for various diseases, including rheumatoid arthritis, that affect the muscles and joints, as well as their surrounding tissues.

taking on better paid or full-time jobs due to the disease (Kvien, 2004). A cross-sectional study conducted in Australia with people with rheumatoid arthritis aged 18 to 65 years describes that almost half of participants who were employed have reduced their work hours (Shanahan et al., 2008). Diminished effectiveness at work does cause additional indirect costs (Kvien, 2004).

Katz et al. (2003) have also highlighted that the need for assistance in mothering should be assessed as this need may further increase rheumatoid arthritis-related indirect costs. Mothers with rheumatoid arthritis who are of employable age might be perceived by some as an economic threat to society as they might be challenged in continuing paid employment as well as taking on the role of the informal caregiver within the family; both dimensions cause increased costs.

Social construction of work-disability

The estimation of work disability and its impact on society may vary depending on the social construction of concepts and terms that allow the assessment of work disability. A review of cross-sectional and longitudinal surveys that have been published between 1980 and 2002 on work disability in people with rheumatoid arthritis, shows variations in the use of terms across studies: work disability was defined as being on disability benefits, having stopped work due to rheumatoid arthritis, or having reduced working hours (Verstappen et al., 2004). Varying institutional definitions of unemployment, disability, and permanently sick across countries lead to challenges in cross-national research and make also the social construction of these concepts within the respective social context clear (Erlinghagen & Knuth, 2010). Possible explanations therefore are the differences in health insurance and social security systems, and thus access to services and social benefits. Higher percentages of work-disability may actually result partly out of the definition of work disability applied in a respective study. These insights exemplify how work disability and subsequently the 'burden' of rheumatoid arthritis is socially constructed.

Tackling the burden of rheumatoid arthritis

To ‘tackle the burden’¹⁰ of rheumatoid arthritis several national and international efforts and working groups have been initiated: for instance in 2000, the decade from 2000 to 2010 (Bone and Joint Decade) was dedicated to improve the health of people with musculoskeletal diseases through a global campaign – supported by the United Nations, the World Health Organization, and others (Woolf, 2000). Furthermore, networks and project-groups have been found to further understand and subsequently address the societal impact of rheumatoid arthritis in society: in Canada, the Episodic Disability Network (EDN) was found and “brings together organizations working on issues affecting people with episodic disabilities and serves as a pan-Canadian forum for issues relating to episodic disabilities” (EDN, 2011). In Europe, project-groups such as eumusc.net (eumusc.net, 2011) and Fit for Work (Fit for Work Coalition, 2011) have been launched. eumusc.net is a project supported by the European Commission, by EULAR, as well as more than 20 scientific and patient organizations across Europe, and aims to optimize and harmonize standards for care of musculoskeletal diseases across the European Union (eumusc.net, 2011). Fit for Work is an initiative with a particular interest in the social and economic impact of musculoskeletal diseases across the European Union. Particular emphasis is also given on the cost-effectiveness of early interventions to improve return to work practices and sustain and strengthen work participation of people with musculoskeletal health conditions (Fit for Work Coalition, 2011).

These efforts and working groups illustrate that resources are invested to ensure that the socio-economic impact of rheumatoid arthritis along with other musculoskeletal diseases or episodic disabilities are minimized. In the literature presented so far in this section, reference to the ‘social’ is only in respect to the threat or burden that individuals with rheumatoid arthritis cause to society, and how this burden can be minimized. When reviewing other literature from a social perspective, I gained further understanding about the processes that go into social constructions of individuals with rheumatoid arthritis as

¹⁰ ‘Tackling chronic diseases’ is a phrase used by Busse et al. (2010) as part of their book-title.

deviant (e.g. Clarke, 2010; Weitz, 2007). Furthermore, social perspectives informing public health literature, such as the body of knowledge on social determinants of health, focuses not solely on the socio-economic impact of certain diseases. Thus, I explore in the next section some literature about a social perspective on disease and illness.

3.2 Social perspectives on managing daily life with rheumatoid arthritis

From a social perspective, chronic illness such as rheumatoid arthritis refers to a reality that has to be negotiated at the interface of the individual and the social context. This reality is informed by, and yet goes beyond biological entities and socially shaped conditions (Gabe, Bury, & Elston, 2004). For example, in relation to women with rheumatoid arthritis, a social perspective would underlie research that seeks to disclose how the daily life of the women is shaped and constituted by the social conditions in which they go about their daily lives. The impact of rheumatoid arthritis would then be not seen as a purely medical condition causing bodily limitations and functional restrictions, but also as a socially shaped condition with a moral status. For instance in regard to work-disability, the focus would not solely be on describing features of the individual such as functional impairments, but also how social systems and structures shape social norms and open up varying possibilities for participation of women with rheumatoid arthritis in society.

Social norms and values

In several ways, social perspectives on health and illness point to how the actual doings of persons experiencing illness are contextualized within particular norms and values. A particular social order exists in any society that is maintained through the norms of the respective society. Individuals experiencing illness are often challenging social values, beliefs, and norms as their bodies do not necessarily fit into such social norms (Wendell, 1996, 2008). Any form of deviance constitutes a threat to this social order (Clarke, 2010; Weitz, 2007). Such a threat has been investigated in socio-economic terms in arthritis-related literature as outlined in the preceding section. The changes and processes of adaptation due to rheumatoid arthritis are then not only described in terms of the disease

activity or the coping of the individual but are also judged based on social norms and values. The moral element marks a clear distinction between the medical and social perspective (Weitz, 2007): the medical perspective refers to illness as an objective label which does not bear any moral element. From a social perspective, illness is described as a social construct which in turn indicates a moral status and a form of deviance. The moral status points to the worthiness of an individual and entails a judgment of the human body and the processes within the body (Weitz, 2007). Deviance is not in itself immoral, “rather, deviance refers to behaviors or conditions that socially powerful persons within a given culture perceive, whether accurately or inaccurately, as immoral or as violating social norms” (Weitz, 2007, p. 129). If individuals with rheumatoid arthritis are solely described in terms of their continuous functional limitations and these limitations are perceived as inhibiting the employability of an individual without taking the actual requirements and demands at work into account, the individual with rheumatoid arthritis may be seen as not being able to participate fully in paid work, and thus, in society. Such a judgment would also be a statement about the worthiness of this individual to society. However, one of the critiques of social theorists addressing illness as deviance is that these theories are of limited usefulness in regard to chronic illness. Theories on illness-as-deviance are most salient in sociology (Cockerham, 2010). In contrast to acute illness, chronic illness develops slowly, is most often incurable, and therefore, long in duration. Lupton (2003) points out “[i]n these cases, chronically ill or disabled patients must adapt their role, ‘manage’ their illness and accept impaired functioning as a normal state rather than a ‘deviant’ state” (p. 98).

A social perspective also reconceptualizes the role of health professionals, extending beyond caring or curing functions to that of being an agent of social control. In particular, the medical profession has been proposed as functioning as a social control agent in society through regulating access to services and social benefits. As social control agents, physicians are assigned to decide who is in need of receiving which treatments as well as who is eligible for social or disability benefits (Clarke, 2010). In reference to the Austrian system, examples therefore are the dependence on a physician’s report when disability benefits are assigned or invalidity pension is granted, and the continuation of full child care allowance is also dependent on predetermined visits to the doctor (see Chapter 1).

The importance of considering the influences of social norms and values, and the ways in which social control agents shape possibilities for resources, is further supported by research regarding factors that influence the maintenance of paid employment in individuals with rheumatoid arthritis. Such studies have found that neither disease status from a purely biomedical perspective, nor disease status as it is experienced by the individual, were factors that would fully explain or predict work-participation in people with rheumatoid arthritis (Reisine et al., 2001; Wikström & Jacobsson, 2005). Such findings suggest that health is influenced by many factors that extend beyond medical factors, such as the social construction of disability as outlined in this section, but also by factors that may refer to the living conditions and circumstances of the individual.

Social determinants of health

Scholars in public health have emphasized that a person's health is influenced by many factors that fall traditionally outside the influence of structured health systems (Marmot, 2006). The literature on social determinants of health constitutes another body of literature that shows that understanding health, and what people do in daily life, requires attending to a range of determinants beyond medical condition or health care received. As defined by the World Health Organization (WHO), such social determinants encompass:

“The social determinants of health are the circumstances in which people are born, grow up, live, work and age, and the systems put in place to deal with illness. These circumstances are in turn shaped by a wider set of forces: economics, social policies, and politics” (WHO, 2011b).

Research about social determinants of health has shown that different socio-economic groups experience varying degrees of health (Raphael, 2010). Along these lines, researcher interested in social determinants of health referred to the phenomenon of the social gradient. This phenomenon directs attention to how health status changes gradually along with one's social position (CSDH, 2008). In other words, the higher the social position of an individual, the better her health; the lower the social position, the worse the health. Advantages assigned to social position do not only refer to financial resources to buy, for instance, health care services, but also to having access to social networks that

may provide helpful information or access to services, making use of information, or gaining information (Marmot, 2006).

Research about the social gradient is informed by a life course perspective and integrates biological and social elements that shape the life of the individual (Raphael, 2010). For instance, living circumstances in early life (including nutrition, housing, and schooling) become engrained in the physiology and pathology of individuals. Furthermore, social advantages and disadvantages, which an individual experiences throughout the course of life, have cross-sectional and longitudinal implications (Blane, 2006). Cross-sectional implications underscore that advantages or disadvantages in one sphere of life are probably similar in other spheres; for instance bad housing is often accompanied by worse working conditions. In addition, longitudinal implications stress in particular the life course perspective and highlight that people who enjoy advantages in one sphere of life likely succeed in other spheres of life; for instance someone with good schooling is more likely to succeed in securing better working conditions.

Critical social transitions

Throughout the course of life the social position of people can change as they move from primary to secondary school, leave school and enter the labor market, leave the labor market to retire from paid employment, or experience the onset of a chronic disease. These changes are referred to critical social transitions. The favorableness of the outcomes of these transitions is influenced by previously accumulated advantages and disadvantages. For example, research has shown that people with social advantage – defined as people who are assigned to higher socio-economic groups such as professionals and managers – are more protected against exclusion from the labor market after onset of chronic illness than semi-skilled or unskilled manual workers (Blane, 2006).

In literature related to work disability of individuals with rheumatoid arthritis, people with work disability are often referred to as being older, less educated, and making lower wages before disease onset (Verstappen et al., 2004). This example raises for discussion whether the onset of rheumatoid arthritis is such a critical transition and if it leads to less

favorable outcomes for individuals with rheumatoid arthritis who have reached a higher age, have less formal education and earn less. The individuals captured within this group may have already accumulated certain social disadvantages over the course of their lives that makes them more vulnerable to work disability. Such assumptions are supported by research on work disability in people with rheumatoid arthritis: people with higher education have been more likely to sustain employment because higher education has provided them with resources such as access to increased possibilities and flexibility at the labor market (Kaptein, Gignac, & Badley, 2009). It is not only the greater possibility and flexibility within the labor market, but also the nature of work is likely to be less physically demanding with increased education (Li, Sundquist, & Sundquist, 2008; Plach et al., 2005; Reisine et al., 2001).

In a study conducted in the United States, individuals with rheumatoid arthritis described several factors as influential in continuing or maintaining employment; these factors included the prestige associated with a job, the physical demand, the amount of hours, and the form of employment (e.g. self-employed; Reisine et al., 2001). A cross-sectional study conducted in Canada with individuals with rheumatoid arthritis described also family composition as an influential factor: for single women, regardless of children, marital status is a predictor for being out of the labor force; for men marital status did not matter, and having children actually reduced the risk of being out of the labor force (Kaptein et al., 2009). For women, particularly for single women, a part-time income may not provide enough income as a means for existence and it may only provide limited access to full health care and social benefits. Consequently, going on disability benefits might be a more realistic solution (Kaptein et al., 2009). A qualitative, narrative study conducted in Austria offers complementary insights. Austrian men diagnosed with rheumatoid arthritis described abandoning employment as a challenge in a society that is largely structured around the male-breadwinner model; whereas for women with rheumatoid arthritis opting out of paid work and engaging in socially or culturally valued activities such as establishing a self-help group or writing books about the history of one's hometown might be well accepted (Stamm et al., 2008).

These insights illustrate that the living conditions of women with rheumatoid arthritis are determined by factors that go beyond biomedical factors. Such factors include resources and possibilities that open up within the actualities of daily life and are circumscribed by varying organizational processes and social relations. These organizational processes and social relations become crucial to take into consideration to comprehensively understand how mothers with rheumatoid arthritis go about their daily lives.

3.3 The need for research about the situated nature of how Austrian women with rheumatoid arthritis go about their daily lives

In this chapter I have started with a review of literature that has taken a social perspective on the lives of people with rheumatoid arthritis. This body of literature has focused primarily on the socio-economic impact of the disease on society. In the next section I have outlined some literature about the social construction of disability, referred to some characteristics of a social perspective on illness, and addressed literature on social determinants of health that acknowledges how life circumstances and conditions influence health. In contrast to literature discussed in the second chapter, which has its primary focus on the individual, is disease-oriented, and medically dominated, the literature reviewed in this chapter directs attention to a societal rather than individual level. I argued already in the first chapter for the need of knowledge generation about the actualities of everyday life and how everyday life becomes shaped through the social context. Such an argument is in line with the call for research about the situated nature of occupation in occupational science. In the remainder of this chapter I aim to clarify why research is needed about the situated nature of how Austrian women with rheumatoid arthritis go about their daily lives.

Throughout previous chapters, I have argued that research about the daily lives of women with rheumatoid arthritis has to take the social context into consideration to fully understand how women go about their daily lives. Furthermore, in the synopsis about the social context of Austria (see Chapter 1) I have pointed to some particularities and values shaping the Austrian context; in particular the emphases on the traditional family model and participation in employment.

The insights gained about social determinants of health and the social gradient are closely related with the structure of a social welfare state (Eikemo, Huisman, Bambra, & Kunst, 2008; Raphael, 2010). Social welfare refers to the state's role and responsibility in providing some basic modicum of welfare to its citizens, including the domains of health, education, housing, social benefits and services to prevent unemployment and poverty. An important aspect of welfare provision refers to income maintenance in cases of unemployment or sickness (Bambra & Eikemo, 2009). This aspect is important to take into consideration in regard to the body of knowledge about participation in employment of individuals with rheumatoid arthritis, and in regard to situation of women in the Austrian context. In arthritis-related literature it is highlighted that participation in employment is often challenging for individuals with rheumatoid arthritis (e.g. Backman, Kennedy, Chalmers, & Singer, 2004; Kessler et al., 2008; Nilsson et al., 2007). Furthermore, lower education has been described as one of the predictors for work disability in individuals with rheumatoid arthritis (Kaptein et al., 2009; Verstappen et al., 2004). In Austrian women, part-time employment is a rather typical form of employment (Knittler, 2010; Notz, 2010). At the same time, various social benefits depend on previous social insurance periods, whereby social insurance depends on employment (BMASK, 2010b). Thus, when considering the situation of a woman with rheumatoid arthritis, her educational background and employment situation, along with the social benefits and services provided by the Austrian social welfare state, the need for attending to the interaction between social determinants of health and the welfare state structure becomes more evident.

However, except for research conducted by the research group of Tanja Stamm (e.g. Stamm et al., 2008; Stamm et al., 2009; Stamm et al., 2010), I was not able to locate any literature that focused on the daily lives of women with rheumatoid arthritis in Austria. When it comes to employment or motherhood and rheumatoid arthritis and its interaction with the social system in particular, I am not aware of any study conducted in Austria. This constitutes a chasm in knowledge: hence, I urge the need for knowledge generation about how Austrian mothers with rheumatoid arthritis, who are of employable age, go about their daily life. Such knowledge would facilitate understanding about the situated nature of their doings in their daily lives in the Austrian context.

In this dissertation I am particularly interested in how Austrian women with rheumatoid arthritis go about their daily life as it is situated within a social context that may open up varying resources and possibilities. Given the strong emphasis on family and employment in Austria, I aim to explore how Austrian women, who are of employable age, mother of at least one child, and diagnosed with rheumatoid arthritis go about their everyday lives, and how their daily lives are coordinated to organizational processes of arthritis-related health care and beyond. Exploring how the women's doings are coordinated to organizational processes contributes to understanding about the situated nature of occupations. It requires a research approach that allows bridging the actual living contexts of individuals with the socio-political dynamics and processes at play in a given context. I agree with the institutional ethnographers Campbell and Gregor (2004) that it is important to explore the actual determinants of people's life conditions, and posit that institutional ethnography provides a social theory and method to do so.

Chapter 4

4 Institutional ethnography: A conceptual framework for inquiry

I aimed with this institutional ethnography to explore the work that Austrian women with rheumatoid arthritis who are mothers and of employable age do in going about their daily lives as they are situated within the social context of Austria. Institutional ethnography is a social scientific approach that has been developed by the Canadian sociologist Dorothy Smith. Her aim was to provide a conceptual framework that attends to the actualities of people's daily lives (Smith, 2005). Work, in the institutional ethnographic sense, encompasses any activity that people do that requires time and effort, and has intent (Smith, 1987). Therefore it starts right at the experiences of individuals as they are in their bodies, active at actual places in actual time, and as their doings are coordinated with those of other people. The coordination of people's work with the activities of others across time and place points to the understanding of the social inherent in institutional ethnography. Institutional ethnography is grounded in the ontology of the social and offers an approach to make the social visible (Smith, 2005). Thus, institutional ethnography is a conceptual framework of inquiry that supported me well in my aim to explore the actual work of Austrian mothers with rheumatoid arthritis in their daily life as it is situated within the social context of Austria. The analytical focus of institutional ethnography is on explicating social relations as they become accomplished. This chapter outlines the conceptual framework of institutional ethnography and the research process of this dissertation research.

4.1 Starting with women's experiences

Smith articulated that her concern is not about epistemology (Smith, 2005), that is, "the process of thinking. The relationship between what we know and what we see" (Lincoln et al., 2011, p. 103; printed in italics in original source). But rather, institutional ethnography is concerned with ontology, a theory of reality, that provides "a guide to the aspects or dimensions of actual ongoing social processes, in time and in place (...) a conceptual framework for selective attention to actualities such that the project of inquiry

can proceed as discovery of and learning from actualities” (Smith, 2005, p. 52). Hence, institutional ethnography can be seen as a conceptual framework for, or method of inquiry, a social scientific approach, a social theory and method to explore how daily life is accomplished through the coordinated activities of people, rather than a methodology to explain human behavior. The standpoint of women and the ontology of the social provide significant conceptual foundations for the social scientific approach of institutional ethnography.

4.1.1 The standpoint of women

Starting in people’s daily lives, with their bodily experiences in everyday life as it happens in actual time and actual place is what is referred to as the standpoint¹¹ of people in institutional ethnography (Smith, 2005). Starting with the standpoint of people allows exploring how concepts, theory, and discourse are engrained in the actualities of women’s practices and activities (Smith, 1999).¹² It allows gaining access to people’s tacit knowledge, that is, knowledge “known in the doing, and often not yet discursively appropriated” (Smith, 1997, p. 395). Taking on a women’s standpoint should not be confused with standpoint theory and its sometimes delusive implication that the knowledge gained by those who inhabit particular standpoints is privileged (Wylie, 2003). A “women’s standpoint returns us to the actualities of our lives as we live them in the local particularities of the everyday/everynight worlds in which our bodily being anchors us” (Smith, 1997, p. 393).

Standpoint is not a social position or category, but rather it “creates a point of entry into discovering the social that does not subordinate the knowing subject to objectified forms of knowledge of society or political economy” (Smith, 2005, p. 10). Standpoint is integral

¹¹ I used the term standpoint in singular form throughout the dissertation. My intent was not to point to a unitary standpoint but rather to underscore that by taking a standpoint the point to start is in the actualities of an individual that is situated in an actual context at a point in time.

¹² Smith started with offering a sociology for women that starts from women’s standpoint and opened it up into a sociology for people (Smith, 2003). I refer mainly to a standpoint of women throughout this dissertation as I conducted this research with women; however, I acknowledge that the sociology for people as developed by Smith is inclusive for any person in society.

to institutional ethnography, or as Turner (2003) underscores, it is a “methodological stipulation” (p. 74). Inquiry that starts from the standpoint of women begins in their actual lives. The traditional dichotomy between body and mind is collapsed as the starting point is the experience of the embodied knower. The body is not theorized, but acknowledged as the site of knowing (Smith, 2005). Standpoint refers back to the materialist method suggested by Marx and Engels in ‘The German Ideology’ that insists that “we are talking about a world that actually happens” (Smith, 1987, p. 123).

Starting this institutional ethnography at the standpoint of Austrian mothers with rheumatoid arthritis meant to start with their experiences in going about their everyday lives as embodied knowers. Experience becomes available as it is spoken or written, hence, it is dialogical; “[e]xperience is shaped, structured, known socially” (Griffith, 1998, p. 369). The social links back to the materialist method, which indicates that the social exists “in and only in actual people’s actual activities and practices” (Smith, 1987; p. 123).

4.1.2 The ontology of the social

I have argued for the need for attending to the social context to further understand the actuality and complexity of the daily lives of mothers with rheumatoid arthritis. Smith makes a very distinct reference to the ‘social’. She proposes a sociology that is based on an ontology that recognizes that the social evolves through the coordinating of actual individuals’ activities under given material conditions (Smith, 1999). Seeing the social as the concerting of people’s activities is a shared understanding with other scholars such as symbolic interactionists, and ethnomethodologists (DeVault & McCoy, 2006).

The conceptual framework informing institutional ethnography draws upon the thinking of the symbolic interactionist Herbert Mead in regards to the self. Mead referred to the self as being essentially dialogic as it continuously develops in social acts and through communication. Also objects, symbols and meanings come into being in social acts. This understanding of the self and social acts does not account for how pre-existing language may have a powerful role in determining what is said and what can be said (Smith, 1999). Valentin Vološinov and his thinking about the inter-individual territory, and Mikhail

Bakhtin's understanding of utterances and speech genres accounts for the existence of language prior to people's interactions. Vološinov argues that words are determined by meaning assigned to the words by the speaker and listener. This reciprocal process occurs in the inter-individual territory. Such an understanding is very similar to Mead's reference to symbolic communication. In contrast to Mead, Vološinov believes though that language has a formative character in what people can mean (Smith, 1999). Bakhtin's thinking has been particularly salient in institutional ethnography in regard to language (further details are given in this chapter's section on Language and discourse) and his

“conception of the meaning of words as already sedimented by past activities and hence as determined prior to a given moment of speech or writing, but he also insists on meaning as produced and shaped in the local historical contexts of utterances. Concrete utterances are essentially dialogic, an active interplay between past determinations of meaning and their creative shaping to the speaker's or writer's current intentions” (Smith, 1999, p. 113).

Thus, essentially the social is an ongoing historical process. Any social act or communication occurs in a setting whereby the setting itself is only constituted as such through the people who are active in the respective setting (Gardiner, 2000). Any activity occurs in a setting to which it relates and from which it should not be separated. This conception points to another important theoretical foundation of institutional ethnography, namely ethnomethodology and its reference to the indexical character of activities. Indexicality, as described in ethnomethodology, directs attention to the context-dependent and situated nature of any practices and accounts (Garfinkel, 1967). Attending to indexicality implies acknowledging context, the actualities of people's accounts, as part of people's activities and not external or separated from it (de Montigny, 2007).

Ethnomethodology aims to “develop practical understandings of the everyday accomplishments of (...) recognizably ordered social scenes” (de Montigny, 2007, p. 97). The ordered social scenes, such as managing rheumatoid arthritis, being a mother, or reconciling work and family, become accomplished through women's ordinary, mundane, everyday work. In turning analysis away from abstracted concepts toward the

actual practices of people, ethnomethodology comes close to the methodological demand that Marx and Engels were pointing to, namely an inquiry that accounts for people's real lives (de Montigny, 2007). Ethnomethodology makes any inquiry inherently reflexive. It challenges anyone involved to reflect upon how is it that a family meal time, a disease activity score, or one's employability status becomes accomplished. Ethnomethodology, however, is limited in its capacity for ethnography to move beyond the common sociological practices of describing and conceptualizing the social (Smith, 1990b). Institutional ethnographers attempt to move further by explicating, rather than explaining, the social relations in which people's coordinated activities are embedded.

4.2 Social relations

Social relations imply that the experiences and actual activities of people in local sites are engrained in sequences of action that coordinate the activities of various people in multiple local sites. The reference to social relations in institutional ethnography is informed by Marx's thinking:

“Social relations for the sociologist refer to the abstracted forms of normative structures held to link positions or roles (...). For Marx, by contrast, social relations are the actual coordinated activities of actual people (...). Relations are not norms, concepts, or structures apart from activities, determining and being expressed through activities. They are coordinated or articulated processes of action among persons taking place in time and having determinate form. Social relations are thus sequences which no one individual completes” (Smith, 1990b, p. 94).

Social relations coordinate the activities of people across time and place, however, they remain largely invisible. Institutional ethnography aims to explicate how activities in local settings are related to activities of people elsewhere; the latter is referred to as the extra-local or trans-local settings. The conception of local and extra-local settings and relations is especially noteworthy as it rejects the dichotomy between micro and macro and builds on the ontology of the social. For instance, when a mother brings her child to day-care as she has an appointment at the hospital, her work is coordinated to the activities of the person providing day-care and to the hospital setting where the woman has already arranged an appointment with the receptionist previously, and the receptionist as well as the health professionals would await her on time. This simple example shows

how activities of various people across time and place are related without being necessarily visible. To the receptionist at the hospital it is not visible that the child is cared for by somebody else at the same time, that the child had to be dropped off at day care prior to the appointment at the clinic, and that the child has to be picked up afterwards. Institutional ethnography, as a method of inquiry, aims to discover and explicate these social relations. It is a discovery of how what is going on in everyday life is organized across settings. Seemingly ordinary and effortless activities such as attending an appointment at the hospital are socially organized. Hence, acknowledging the social relations inherent in the daily lives of mothers with rheumatoid arthritis and explicating the social relations in which mothers with rheumatoid arthritis go about their daily lives allows for a comprehensive understanding about the complexities of their everyday life.

Significance of texts in institutional ethnography

Texts have a mediating character in the social relations (DeVault & McCoy, 2002; 2006). Texts, which are any kind of document, photograph, drawing, video, sound recording, or representations, have a fixed and replicable character. They can be stored, copied, transferred and distributed to become subsequently activated by users at different places at different points in time. Thus, incorporating texts into institutional ethnography allows explicating how a text that is read, completed, or signed in a local setting coordinates the consciousness and activities of the individual to trans-local relations. For instance, in a health care setting health records are taken up, read and written in by health professionals; the records, however, go beyond this particular work setting as what is written down, such as treatment plans or a plan for further examinations, happens mostly at work settings such as in the pharmacy, laboratory, or people's homes. Understanding texts then in the ethnographical sense is to explore how texts are active in the social relations and coordinate the actual work of people between and across local and trans-local settings.

Texts are interesting in their material and symbolic form for institutional ethnographers. Through their replicable and fixed character texts have a material form and can be transferred and disseminated to people who are active at different times and different

work settings. The symbolic form of texts becomes evident through their mediating power within social relations. Texts speak to the reader once she takes the text up and reads it. The ideas and words contained in texts are not isolated but rather invite the reader into a conversation that becomes enacted once the text is read (Bell & Campbell, 2003). This process of the text being enacted is referred to as the text being active (Smith, 1990b, 1999). The distinction between reading and interpreting a text is crucial. In the text-reader conversation

“one side of the text is obstinately fixed and unresponsive to the reader’s interpretations. The reader activates the text. (...) she takes up its words. They become in a sense hers as she activates their meaning. (...) Interpretation lies in the other part of the text-reader conversation, her response to what she reads” (Smith, 2003, p. 155).

The institutional ethnographer’s interest in texts is not in understanding how texts are interpreted by individuals, but rather in understanding how texts coordinate the activities of people across different work settings (Smith, 2006). The “constancy of the text is also key to the effect of institutional standardization across multiple local sites of people’s work” (Smith, 2005, p. 108). Some texts are active, that means they are read, filled in, forwarded by people active in particular work settings; other texts such as regulatory texts provide the frame of reference for active texts but would not become visible in the actual work setting. For instance a woman would have to fill in a form to get unemployment benefits; this form would be the active text. Moreover, in this form reference would be given to the legal frame of unemployment benefits; while the legal text would not be necessarily active in the work setting, it would still provide the legal frame of reference for concepts used in this setting and for organizational processes within the work setting.

Texts establish concepts and categories that coordinate people’s consciousness into these relations (Smith 2006). Hence, textually-mediated relations are ruling relations. When people use concepts and refer to them, they become common sense, and the ruling relations become invisible (see Ng, 1995). People who are ruled and participate in ruling are familiar with these concepts and they become common sense to them (Walker, 1995). Attending to texts is integral to institutional ethnography to disclose how activities of

people across different work settings are coordinated and socially organized. For the individual active in everyday life, the coordination of her work to trans-local relations is not necessarily visible. However, starting from the individual and tracing how her work is coordinated to trans-local relations makes visible how these relations extend beyond to what is visible within the local setting. Explicating how the local work of women with rheumatoid arthritis is coordinated to and ruled within trans-local relations, opens up an understanding of the situated nature of what the women do in their daily lives.

4.2.1 Ruling relations

The ruling relations are not something abstract existing “out there”. Rather, it is the ruling relations that abstract the activities of the individual in everyday life into a “technological and technical specialization, elaboration, differentiation, and objectification“ (Smith, 1999, p. 77). Explicating these ruling relations allows “for the inquiry into ideological practices” (Turner, 2003, p. 76). Ideological practices refer back to Smith’s interpretation of Marx and Engels ‘The German Ideology’ and point to the practices that allow for the confinement of people’s actual activities to a conceptual level. Concepts become substitutes for a reality that is lived by actual people in actual time and place. “Ideology can be viewed as a procedure for sorting out and arranging conceptually the living actual world of people so that it can be seen to be as we already know it ideologically” (Smith, 1990a, pp. 42-43).

For instance, the concept of health status in people with rheumatoid arthritis represents a synthesis of concepts such as pain, disease activity, and functional status. The actualities of people in their daily lives become confined to these concepts. The procedures of reporting and assessing pain, the procedures inherent in performing laboratory tests to estimate disease parameters, the performance of joint assessments, and so on are part of the ideological practices that allow for the arrangement of people’s experiences into what is eventually known as health status. Hence, “[t]o think ideologically is to think in a distinctive and describable way, (...) it identifies methods of reasoning that confine us to a conceptual level divorced from its ground” (Smith, 1990a, pp. 32-33).

Once an individual picks up a text she or he “activates” the text (McCoy, 1995). This text-reader conversation represents a process of translating the actual activities of the individual into the institutional. ‘Institution’ in institutional ethnography points to the organization of a complex set of relations around a distinct function such as health care, education, or mothering (Smith, 1987; 2005). Work, as it is used generously in institutional ethnography, includes “the actual doings that go on to making institutions happen, whether they are recognized in institutional discourse or not” (Smith, 2005, p. 157). Whether work is recognized or accounted for in institutional discourses is also dependent on the concepts that are part of the discourse. Such concepts constitute terms that are abstracted from the realities of what individuals actually do in their daily lives. Thus, the reference to language and discourse in institutional ethnography is worth further exploration.

4.2.2 Language and discourse

For institutional ethnographers discourse happens and exists in bodily experiences, and it does not vanish even if it is not observable; moreover, in the bodily experiences of people as they happen in the actualities of time and place, there are experiences that cannot be spoken or written about within a given discourse. Hence, in institutional ethnography,

“[d]iscourse is not ‘jargon’ or a kind of language. It is not ‘objectification’ or ‘ideology’ that has power. Rather, discourse is specifically the practices through which people bring a particular ‘sequential grammar’ ([Smith] 1999:124) into the local accomplishment of activities. (...) The discourse provides, in text, image, and language, a world participants can find in common that functions to coordinate dialogue sequences in which divergent consciousness are coordinated and unitary agency is produced” (Turner, 2003, p. 94; text in squared brackets added)

Turner’s reference to Smith’s use of the term ‘sequential grammar’ points to the relevance of Bakhtin’s work in the institutional ethnographer’s understanding of language and discourse. Consistent with the ontology of the social, language is seen as relational, inter-individual, historically sedimented and processual, drawing on foundational work by Mead, Vološinov and Bakhtin (Smith, 1999). Language as a means to coin concepts is a very powerful tool. Particular concepts become a means to inter-individually organize consciousness. Bahktin (1981) states

“language is not a neutral medium that passes freely and easily into the private property of the speaker’s intentions of others. Expropriating it, forcing it to submit to one’s own intentions and accents, is a difficult and complicated process” (p. 294).

Knowing the language used and inserting it properly within a particular setting can be seen as moments where discourse is in action. This action constitutes a continuous reproduction and remaking of discourse (Smith, 2005). The utterances generated by the discourse, or speech genres to use Bakhtin’s term, organize the consciousness of individuals:

“Language is realized in the form of individual concrete utterances (oral and written) by participants in the various areas of human activity. These utterances reflect the specific conditions and goals of each such are not only through their content (thematic) and linguistic style, that is, the selection of the lexical, phraseological, and grammatical resources of the language, but above all through their compositional structure. All three of these aspects – thematic content, style, and compositional structure – are inseparably linked to the whole of the utterance are equally determined by the specific nature of the particular sphere of communication. Each separate utterance is individual, of course, but each sphere in which language is used develops its own relatively stable types of these utterances. These we may call speech genres” (Bakhtin, 1986, p. 60).

Bakhtin distinguishes between primary speech genres that are mainly based on experiences, and secondary speech genres. Secondary speech genres are more complex, are mostly written and include for instance scientific writings. When transforming primary speech genres into secondary speech genres their immediacy in actual reality is lost (Bakhtin, 1986).

Bakhtin’s distinction between primary and secondary speech genres allows for a distinction between experience-based and text-based inter-individual territories. Primary speech genres refer to experiences grounded in the actualities of the individual, whereas secondary speech-genres occur on a conceptual level. The inter-individual territory that informs secondary speech genres refers to concepts, such as disease activity and functional status, and their coordination to the ruling relations. Smith (2005) pointed out “[w]hile, in a sense, the experiential is never displaced, the ground on which interindividual territories are built differs radically in the move from primary to secondary speech genres” (p. 86-87). Bakhtin’s understanding of language, more

specifically his understanding of secondary speech genres, has been particularly relevant to institutional ethnography as his work is mainly based on text-reader conversations, in contrast to for instance Mead, who refers mainly to face-to-face conversations.

Smith underscored that the term discourse as used in institutional ethnography is close to “‘secondary speech genres’ (Bakhtin, 1986), a term that corresponds closely to Foucault’s concept of ‘discourse’ and to my usage of the latter term” (Smith, 1999, p. 134). While Smith and Foucault are both interested in exploring how discourses shape the interrelation between people’s everyday lives and the surrounding institutional, social, cultural, and political context (Satka & Skehill, 2011), their reference to discourse is distinct: Foucault’s interest is more on understanding how subjects are created and governed through practices of, for instance, normalization and moralization. Smith argued that “Foucault’s conception of discourse displaces the traditional basis of knowledge in individual perception and locates it externally to particular subjectivities as an order that imposes on and coerces them” (Smith, 2005, p. 17). She highlighted that discourse can be ethnographically explored: institutional ethnographers aim to “rediscover discourse as an actually happening, actually performed, local organizing of consciousness among people” (Smith, 2001, p. 177). Discourse is not happening out there, but becomes into being through the actual activities of individuals.

Institutional discourses lay the foundation and provide terms and categories that allow for people’s work to become institutionally accountable. The transformation from experience into discourse dissolves the immediate reference of words to experiences. When reading a text, concepts and categories are not specified in reference to actual individuals, their activities, or experiences. Rather, institutional discourses subsume the particularities into the institutional, that is, relations organized around a particular function such as health care, or mothering. As such, discourse does not prescribe actions.

4.2.3 Agency and subjectivity

Within institutional discourses individuals are not represented as actual individuals. Rather, “[a]gency is assigned to institutional categories. Someone who can’t be subsumed under the institutional categories assigning agency has no agency” (Smith, 2005, p. 117).

Institutional ethnography is not about exploring subjectivity or agency, but about explicating the social relations by focusing on the agent and using “the subjective as a point of entry into the social” (Smith, 2003, p. 160). Starting with the work of Austrian women with rheumatoid arthritis as point of entry into the social implies that the women, as agent or subject is acknowledged; attention is given to how she experiences the work; how she thinks about the work, how she plans the work, and how the work is coordinated with the work of others.

Smith (2005) writes that the theorizing of actors and people’s actions is a “conceptual transportation” (p. 53) of actual people with their experiences and their actual doings into sociological discourse. As such, actors and actions become abstracted from the ongoing social and historical processes and agency identifies a discursive function. For instance, when completing a form to receive benefits, it says often at the end, “Claimant’s name and signature”. Agency is assigned to any individual who can be subsumed to the category ‘claimant’. No reference is given to an actual individual who is filling in the form, who is dependent on these benefits to sustain her livelihood, who fears to lose the benefits, etc. Nevertheless, once the individual signs the form, the application becomes institutionally accountable and can be further processed. The alternative that Smith has taken on refers back to Marx and Engels and their suggestion to “ground social science in the activities of actual individuals and the material conditions thereof” (Smith, 2005, p. 54). By starting at the standpoint of people, individuals as active subjects are given authority to know based on their experiences of being active in the actualities of everyday life. The focus in institutional ethnography is on the agent, or subject, that is active, and knows based on her own experience (Turner, 2003).

4.3 Studying what individuals do in daily life

The focus of this dissertation is on mothers with rheumatoid arthritis who are active in their everyday lives. Explicating what things the mothers actually do in their daily lives as it occurs within social relations is the main focus of institutional ethnography. Likewise occupational scientists are mainly interested in understanding what people do in their daily lives. While institutional ethnographers refer to the doings of individuals as ‘work’, that is anything that affords time, energy, and has intent, occupational scientists

use the term 'occupation' to refer to anything that people do that brings meaning and purpose to their lives. Hence, in the remainder of this section I aim to clarify my understanding of how work, as used in institutional ethnography, complements the understanding of occupation in occupational science.

Work, as understood by institutional ethnographers, is a powerful means to understand the situatedness of what individuals do in their daily lives as it starts with what individuals actually do as they are situated in the actualities of their everyday lives. For institutional ethnography the meaning or purpose assigned to these doings is not of interest. The actualities underscore the materiality inherent in people's situatedness and take into account the bodily being of individuals in actual time in actual places.

Occupational scientists have been predominantly concerned with understanding the meaning and purpose assigned to what individuals do in their daily lives; to generate such knowledge an individualistic perspective has been frequently used. The critiques on this emphasis in knowledge generation have been outlined earlier (see Chapter 1.4 Situating this dissertation in occupational science) and research about the situated nature of occupations has been called for (e.g. Cutchin & Dickie, 2012; Hocking, 2012; Kantartzis & Molineux, 2012; Laliberte Rudman, 2010).

While alternatives to individualistic perspectives have been suggested by occupational scientists to understand the situated nature of occupations, for instance transactionalism (Cutchin & Dickie, 2012; Dickie et al., 2006), or the governmentality perspective (Laliberte Rudman, 2010, 2012) as outlined in Chapter 1.4, I have argued that such perspectives are limited in generating knowledge that starts at the actualities of everyday life and explores from there how these actualities become accomplished and shaped through the social context. Knowledge that starts in the actualities of everyday life would allow first and foremost to understand how daily life becomes accomplished through the doings of individuals, rather than why individuals are engaging in certain doings.

Furthermore, Kantartzis and Molineux (2012) have argued that in reference to occupation there is a frequent underlying assumption that "a certain kind of activity and a certain way of doing is better than another, and it is this kind of activity that is usually

considered to be occupation” (p. 46). The reference to work “orients the researcher [institutional ethnographer] to what people are actually doing” (Smith, 2005, p. 229; text in squared brackets added), regardless whether it is meaningful or not, whether it falls into the category of productivity, leisure, or self-care.

Hence, institutional ethnography and its reference to work is a promising approach to respond to some of the critiques about the conceptualization of occupation as meaningful and purposeful, and to its categorization into productivity, leisure, and self-care (Jonsson, 2008). As mentioned above, a focus on work allows the researcher to start with the individual but does not rest within an individualistic perspective. Thus, I see work as a promising response to what Magalhães (2012) has pictured, namely that

“by critically reflecting about such tensions as the artificially crafted tension between the individual and the collective perspectives of occupation, occupational scientists may find a common ground on which we will be able to build a new foundation of knowledge” (p. 17).

Institutional ethnography provides a social scientific approach to understanding what people actually do in their local practices and how things are put together and coordinated with extra-local practices. This social scientific approach aims to provide an analytic description of people’s work by drawing on the work knowledge of informants. Work knowledge, which refers to the knowledge that people have of how they do their work and how it is coordinated by and with others, is crucial to understanding what people do in their daily lives. The aim is to understand the varying relations and extended sequences of doing that are not necessarily visible in the local practices but can be disclosed through people’s doings and their work knowledge. Thus, I argue that focusing on people’s work in the institutional ethnographic sense contributes to investigating the situated nature of people’s doings or occupations.

4.4 Translating the conceptual framework into research: The work of Austrian mothers with rheumatoid arthritis

In the previous sections of this chapter I outlined the conceptual framework informing institutional ethnography. Institutional ethnography is a comprehensive social scientific approach to make complex social relations of everyday life visible. As a method of

inquiry, institutional ethnography starts from the standpoint of people and draws upon an all-encompassing understanding of work. The aim of the remainder of the chapter is to clarify the focus of this institutional ethnography, the research process, including recruitment of informants, data collection, and the process toward an analytical description of the informants' everyday lives.

4.4.1 The problematic guiding this institutional ethnography

The interest in institutional ethnography emerged out of the disjuncture that I experienced in my clinical work with women who have been diagnosed with rheumatoid arthritis: the disjuncture occurred between standardized assessments in routine arthritis-related health care in a Rheumatology outpatient clinic in Austria that I was supposed to complete with the women, and complex descriptions women with rheumatoid arthritis provided of their daily lives. While the traditional family model, which includes the male breadwinner, the female caregiver of their children and house-maker, and participation in paid employment are highly valued within the social context of Austria, motherhood, and employment were not addressed in these assessments. This is the problematic from which I started this institutional ethnography. 'Problematic' is a technical term in institutional ethnography and directs the institutional ethnographer to

“the everyday world as an unfinished arena of discovery in which the lines of social relations are present to be explored beyond it. (...) It refers to the translation of an actual property of the social relations or organization of our / people's ordinary doings into a topic for ethnographic research. It locates the step that is taken from the ordinary doings and ordinary language that are the stuff of people's lives onto the terrain of a sociological discourse, the business of which is to examine how that stuff is hooked into a larger fabric not directly observable from within the everyday” (Smith, 2005, p. 39).

The problematic is not the research question to be answered but rather the territory to be discovered (Smith, 2005). Thus, starting with the problematic and taking the standpoint of the women facilitated the exploration of the work that Austrian women with rheumatoid arthritis, who are mothers and of employable age, do in going about their daily lives as their daily lives are situated in and socially organized by the Austrian context. More specifically, I was interested in exploring the social relations that organize and coordinate women's work with arthritis-related health care; as well as to gain more understanding of how the women's work is also coordinated with other relations and organizational processes that may remain unattended and unnoticed in arthritis-related health care, but are organizing the work of these women in their daily lives too.

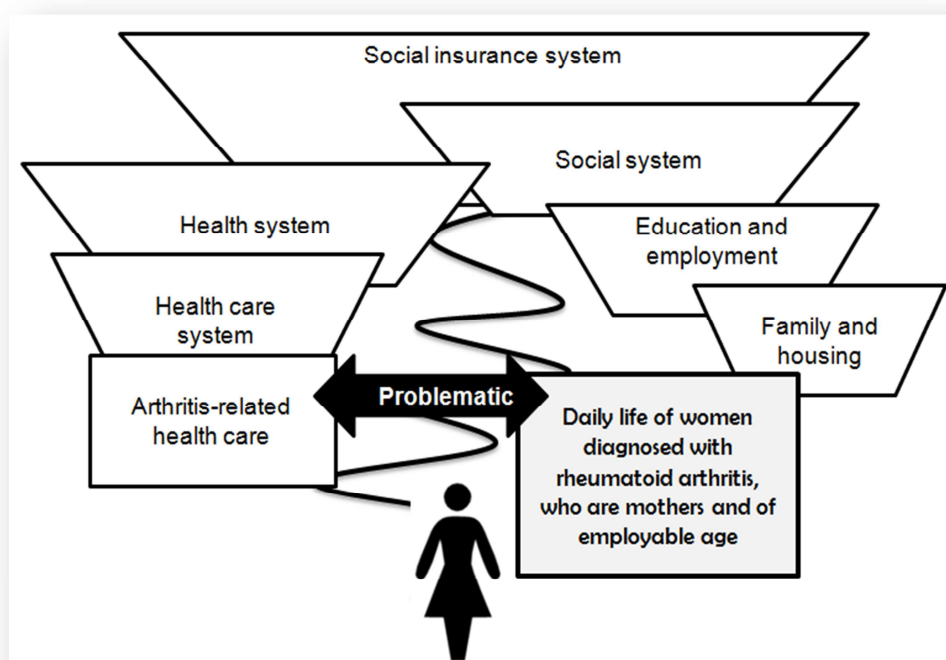


Figure 2: Illustration of the problematic¹³

Figure 2 visualizes the problematic that I had in mind in conducting my research: I started from the standpoint of women in their daily lives to explore how their work is

¹³ Figure 2 was developed within the scope of this dissertation. The representation of the problematic in this figure has been informed by reading Smith's early writings (in particular Smith, 1987; p. 171).

coordinated to social relations given their situatedness within these relations. While the problematic emerged between arthritis-related health care and women's daily lives, I was interested in exploring how the women manage the complexity of their daily lives that may extend far beyond what becomes visible in arthritis-related health care. While institutional ethnography offers a theory and method to revisit these relations and disclose ruling relations (Campbell & Gregor, 2004), it is important to acknowledge that this research has been shaped by my situatedness within the social relations too.

4.4.2 Research relations

In taking up the ontology of the social, any effort toward generating knowledge, such as this research, can be seen as integral to the social relations. Thus, in this section I reflect on my own self, including my personal trajectory that has certainly informed and shaped this institutional ethnography. This section is not meant to be a psychological introspection but rather an engagement in sociological reflexivity (Allen, 2004). In doing so, I acknowledge that this research itself is situated within and shaped by formal and interpersonal relations (Campbell & Gregor, 2004). Reflexivity has been suggested for qualitative research as a means to critically reflect upon the self of the researcher (Lincoln et al., 2011). Altheide and Johnson (2011) argued that ethnography itself is an approach to engage with social life in a reflexive manner. Making the researcher, the researcher's activities, and knowledge claims derived from the research accountable is crucial to ensure credibility and trustworthiness of the study.

Smith (2005) has pointed out that institutional ethnographers have to be critically aware about the capacity of institutional discourses in order to prevent institutional capture. Institutional capture is the conversion of informants' accounts into the terms of an institutional discourse (McCoy, 2006). Institutional capture may happen easily when informants and researchers are familiar with the institutional discourse and know how to speak it. The issue is then that

“the particulars of the informant's local work are displaced by “the organization's organizational account” (...) “Institutional discourse swallows perspective, the local, the particular, and the subjective experience of workers (...) institutional

discourse selects those aspects of what people do that are accountable within it. What is not discursively recognized will not appear” (Smith, 2005, pp. 156-157)

My personal trajectory

I was trained as an occupational therapist in Austria, and graduated from the European Masters of Science in Occupational Therapy program.¹⁴ Discussing professional and practice issues within this international program challenged and enriched my perspectives significantly. Buzzwords such as “cultural, social and political context” become lively rather than abstract concepts. Since February 2007 I have worked as an occupational therapist and research assistant at the Medical University of Vienna, Division of Rheumatology. I have had the opportunity to learn and work with and from an interdisciplinary team and to collaborate in various international research projects, as well as attend and present at international, interdisciplinary conferences (e.g. annual scientific meetings of the ACR, the EULAR, and the CARE¹⁵ conference). My personal transition from Austria to Canada in 2008 to continue with graduate studies in the field of Occupational Science at The University of Western Ontario was characterized by a process of finding my way in another country. This experience made me aware how different societies are structured and organized; how these structures and organizations circumscribe how people go about their daily lives, as well as what topics become salient within public, professional, and academic discourses. Thus, given my personal biography and my socialization into this area of research, I am part of and participate in formal and interpersonal relations that inform this research.

¹⁴ The European Master of Science in Occupational Therapy is a joint Master’s program of the University of Brighton (UK), The University College Sjælland Naestved in cooperation with University of Southern Denmark, the Hogeschool van Amsterdam (The Netherlands), and the Karolinska Institutet (Sweden); since 2010 the Zurich University of Applied Sciences (Switzerland) is also a partner institution. This program has been developed to be achievable while working in the field of study. For more details visit <http://www.ot-euromaster.nl/index.html>

¹⁵ CARE represents a “team of international, interdisciplinary health professionals and patients who aspire to promote, evaluate and shape models of team and non-pharmacologic interventions for (rehabilitative) care in arthritis” (CARE, 2011).

Institutional ethnographers acknowledge that “the production of knowledge is itself integral to ruling relations” (Campbell & Gregor, 2004, p. 68). The way this dissertation is written has transpired within particular ruling relations. As researcher I am part of a scientific community that speaks within particular discourses and is ruled by certain ideologies. For instance, this study has received approval from the Research Ethics Board of The University of Western Ontario, as well as the Research Ethics Board of the Medical University of Vienna. Gaining approval from Research Ethics Board is part of an organizational process, which was initially established within a biomedical framework based on the Declaration of Helsinki that did not address the nature and particularities of social, not even to mention qualitative, research (Guillemin & Gillam, 2004). However,

“we diligently answer the questions on the ethics application form, even though they may be irrelevant to our research. We have learned to write our responses to the questions in “ethics-committee speak.” This involves using language that the committee will understand, is free of jargon, but will nonetheless reassure the committee that we are competent and experienced researchers who can be trusted” (Guillemin & Gillam, 2004, p. 263).

This example of gaining approval from the Research Ethics Board illustrates how this study is ruled also within particular relations. Moreover, I have worked as an occupational therapist in the outpatient clinic at the Medical University of Vienna, Department of Rheumatology, from which informants were recruited. Part of my working time at the Medical University of Vienna was dedicated to research. Being an occupational therapist and member of a health professionals’ research group has been quite uncommon until recently in Austria, nor has it been common to conduct qualitative research in medical settings (Stamm, 2009). Thus, the research group had to find its position within a setting that “follows a biomedical, positivist and natural science understanding of health and illness” (Stamm, 2010, p. 72).

Being an insider and/ or outsider

In ethnographic research, the researcher's position within the research is commonly described in terms of insiders and outsiders. Griffith (1998), a Canadian institutional ethnographer, has described insiders as people whose biography (including gender, class, and history) provides them with a familiarity of the group of people being studied. In contrast, outsiders do not have this familiarity or intimate knowledge of the group. It is noteworthy that insiders are not a homogenous group either (Griffith, 1998): while people may share the same gender, age, and diagnosis they may still differ in other dimensions such as professional status, family status, or ethnicity. While some discussions about the insider and outsider status in ethnographic research have presented a rather polarized picture, Allen (2004) pointed out that this status changes throughout the research process as well as in any interaction with individuals. The researcher's identity as being an insider or outsider is in itself an interactive and socially constructed process that becomes continuously negotiated in the field. Given my work experience, I may consider myself as an 'insider' of arthritis-related health care provision. However, I am certainly an outsider in terms of receiving health care in this setting or due to rheumatoid arthritis, or living with a chronic health condition. Though I am an Austrian woman of employable age, I am enrolled as a full-time graduate student at a Canadian university. Like the informants for this study, I am of child-bearing age, but I am not a mother.

Remaining reflexive on my biography in this research, is crucial to acknowledging that my understanding of the problematic is shaped, likely impeded and also facilitated, by my person (Altheide & Johnson, 2011). Individuals are differently located within the social relations and consequently have different work knowledges. For instance the work of the mother, her partner, her employer, the nurse, the occupational therapist, and the rheumatologist are part of the social relations. However, no account is superior to another (Griffith, 1998). Various points of entry into the problematic are possible (Grahame & Grahame, 2009). Hence, I acknowledge that I am located in various relations related to this study as well. Having this in mind, the aim of this institutional ethnography is not to interpret the daily lives of Austrian mothers with rheumatoid arthritis, but rather to make the social relations visible and discover how things are coordinated at particular work

settings and across settings when starting from these women's experiences and work knowledge.

4.4.3 Informants

In institutional ethnography research participants are referred to as informants (Campbell & Gregor, 2004). Hence, I refer to the women who participated in this study as informants; except if I refer to standard terms such as participant observations. This underscores that informants do not provide the "data" to be analyzed, but rather they share their insights, information, work knowledge and cues as to how their work is socially organized (Smith, 1987). Hence, informants are acknowledged as knowing actors, not transformed into the objects of this study. In institutional ethnography the experience of informants is the standpoint from which to explore the relations, which implies that informants are chosen as relevant to the problematic.

For this study informants were recruited from the outpatient-clinic of the Medical University, Department of Rheumatology based on the following criteria:

- Being a woman who was identified by the gatekeeper as diagnosed with rheumatoid arthritis
- Being between 25 and 45 years of age
- Being a mother with the legal right over her child/ children based on the woman's self-report
- Being a mother of a child that lives at least part-time at home based on the woman's self-report
- Being fluent in German to read, comprehend, sign the consent letter and give ongoing process consent as well as engage in dialogue in German with the researcher

For recruitment, two gatekeepers – a nurse and an occupational therapist – were identified at the Rheumatology outpatient clinic. The gatekeeper identified women who fulfilled the inclusion criteria for this study and passed the women's contact details on to me. Subsequently I contacted these women through phone to provide them with some information about the study. Women who were interested in the study, were asked for a meeting at a place of their convenience to receive detailed verbal and written information

about the study. All women who agreed on a meeting agreed on participating in this study and provided me with their informed consent to participate in this study.

Table 3 contains information about the children, marital and employment status, and educational background of the informants. Informants are between 28 and 41 years of age. I only indicated age ranges of the women and their children, and professional groups here to ensure confidentiality. Moreover, pseudonyms have been used.

Name	Children	Marital Status	Employment status	Educational background
Julia	1 (2 years old)	Co-habitation	Part-time employed	Teacher
Erika	3 (elementary and high school)	Married	Housewife; part-time employment below minimum threshold	Health professional
Veronika	2 (both below 2 years of age)	Married	Maternity leave	Health professional
Lisa	1 (1 year old)	Co-habitation	Maternity leave	Health professional
Marissa	1 (1 year old)	Co-habitation	Maternity-leave; Part-time employment	Business and management
Katharina	1 (high-school)	Divorced	Unemployed; receives social assistance	Trade business
Anna	2 (both in elementary school)	Single	Invalidity-pension	No formal professional training

Table 3: Information about informants

Katharina self-reported in the initial meeting that she has full custody for her daughter and that her daughter lives with her. Throughout one of the participant observations it became evident that her daughter lives with Katharina's parents for most of the time.

Different from other qualitative research, the number of informants in institutional ethnography is not capped until data saturation is reached, which would be up to a point where no new or alternative insights are gained in further data collection (Morrow, 2005). In institutional ethnography informants are providing the information and cues to gain a comprehensive understanding of the social relations. Seven informants have been used by other institutional ethnographers (Jung, 2003; Townsend, 1998): Jung (2003) did an

institutional ethnography on the accommodation of students with chronic illness in postsecondary education in Canada; Townsend (1998) conducted an institutional ethnography in mental health institutions in Canada in regard to how professionals' intentions become overruled by organizational processes and relations.

Townsend (1998) began by collecting data of two informants and based on this data she developed initial analytic ideas. These ideas also triggered further reflections on her part as a researcher and then she went on with further recruitment (Townsend, 1998). I started recruitment with two informants, conducted interviews and participant observations with them and reflected then on the transcripts, field notes, and first analytical ideas with my thesis committee. Similarly to what Townsend (1998) described, at this point the analytical ideas were more reflections upon the research and emerging ideas based on the insights gained from the two informants. Then I continued with recruitment of further informants. By the time I had data collected from five informants, I reviewed all the transcripts, field notes, and my personal notes. I recognized that while I gained a picture about the social relations and related similarities and differences about the daily lives of informants and their social context up to this point, I noticed that I did not have a full picture about the social relations. After spending time with further two informants, similarities were further supported and further differences came to the forefront. As my analytical ideas emerged further along with the data collection, I noticed that these differences are also due to the unique situatedness of the women in the social relations, and the similarities referred to their work as it is coordinated to relations that are ruling organizational processes. As I was particularly and primarily interested in the latter, I completed data collection at this point and emerged fully into the analytical description. In recruiting women consecutively and not more than two to three at a time, I was able to engage with each woman thoroughly and to gain a thick description of what is happening in their everyday lives and beyond by reviewing and tracing relevant texts.

4.4.4 Data collection

Campbell and Gregor (2004) pointed out that very specific data is needed to gain an in-depth understanding of how the everyday work of individuals is coordinated and to be able to map out the social relations. To gain a comprehensive picture of women's work in

their everyday lives as it occurs at different work settings and is coordinated to various work settings, multiple methods – including interviews, participant observations, and identification of texts relevant to the social relations – were performed simultaneously and complementarily. The consecutive approach of recruitment and data collection not only allowed me to fully immerse myself into understanding women’s work knowledge and their daily lives, but also to remain reflexive and flexible throughout the research project. For instance, after the initial interviews with the first two informants I noticed the challenge of moving beyond institutional discourse. These interviews were held in a quiet meeting room at the university. Both informants suggested the university as it was convenient for them to meet there; however, at times I noticed the challenge of going beyond disease-related matters to talk more about their daily lives. To prevent institutional capture, further meetings with these informants as well as initial interviews with other informants were held outside the university-building; if women still preferred to meet nearby the university, we arranged the meeting in a quiet café lounge rather than using a meeting room at the university.

Interviews were audio-taped and transcribed verbatim. Throughout participant observations, conversations were only audio-taped if the informant and I would sit down to have a conversation. These tapes were not fully transcribed: I re-listened to the tapes several times, made notes and transcribed relevant passages.

Interviews

In the scope of institutional ethnography, interviews with informants are crucial to identify the social relations based on their stories (DeVault & McCoy, 2006; Grahame, 1998). In the ethnographic interview informants are encouraged to use their ‘native language’ – meaning that they should talk in the same way as they would with somebody else from their cultural scene (Spradley, 1979). Interviews in institutional ethnography are not applied to reveal subjective experiences, but rather to locate and map the social relations that connect and coordinate the work of various people at different sites. The aim is to get informants’ talk about what actually happens in order to understand their work as it happens in local and trans-local processes (DeVault & McCoy, 2002). As

DeVault (1991) highlighted, “their vocabulary, their particular way to talk, the taken-for-granted concepts that organize their talk, the structure of their accounts, all serves features of the talk that express the social organization of their work” (p. 29).

For this study, the interviews were set up in line with ethnographic interviewing (Spradley, 1979) and institutional ethnographic interviewing (DeVault & McCoy, 2002; 2006). The initial interview was structured by open-ended questions. Informants were asked to describe a fairly typical day of their week, elaborate on what is happening throughout this day, and how this day might be different from other days of the week (for further details see Appendix 1). The final interview was structured around the ongoing analytical description of the respective informant’s daily life. Informants were asked to review mind maps that I made based on my understandings of their daily lives, their work and with whom their work is coordinated based on the interviews and participant observations (Appendix 2). This mapping exercise refers back to ethnographic interviewing (Spradley, 1979). As I illustrated my evolving understandings, I asked informants to elaborate and correct. The actual mind maps include detailed and specific information about informants and are in German language. To protect confidentiality of informants, two exemplary mind maps are attached (Appendix 3). Some questions that I had in mind when I reviewed texts with informants are listed in Appendix 2.

Interviews lasted between 60 and 180 minutes. The interviews took place at various places according to the informants’ convenience; these places included:

- a very traditional old café in Vienna – the informant choose this place as it has always been a special treat for her to go to this particular café and she hasn’t been there for quite some time;
- a café where an informant who moved away from Vienna used to go regularly when she still used to live in Vienna;
- a children’s café, which is arranged very spaciouly so that anyone can easily move around with the baby buggy. The café has a generous playing area for children, and children would walk around and connect with other children – she always wanted to check out this place but never went there before;
- cafés that were located conveniently;
- at the home of informants – either in the kitchen, dining, or living room; a couple of interviews took place in a meeting room at the clinic.

Participant observations

To understand the actualities of everyday life of the informants as they happen in actual places at a particular time is at the core of institutional ethnography and inform the interest in searching out the social relations that happen in the actualities of the everyday life (Diamond, 2006). Participant observations support this aim of institutional ethnography and enable incorporation of places, time, motions, and embodiment in the process of data collection and analysis. Throughout participant observations I dialogued with informants about what they are doing, how they are doing it, and why they are doing what they are doing in the given way (DeVault, 1991). Further details of questions that I had in mind throughout the participant observations are listed in Appendix 4. Participant observations enabled me to explicate the taken-for-granted mundane work that women do in their daily lives and offer an additional approach to understand the social organization of actual work settings (Diamond, 2006).

Informants were informed at the beginning of each participant observation that I would make notes while observing. In case we sat down and discussed any particular topic, the dialogue was audio-taped upon informants' verbal consent. Throughout the course of the research I participated in various things inside and outside informants' homes. The locations and things I observed were decided by the informants based on where they felt comfortable having me present. At informants' homes I spent time with informants throughout morning routines, cooking-time, family lunch-time, and afternoon-routines. Outside their homes I joined for instance a visit to the doctor for a medical examination related to the mother-child pass scheme, a visit to the labor market office (AMS), shopping, an afternoon walk to visit the animals at the neighbor's farm, and the work place of one informant. Immediately after each participant observation I sat down and reflected on my observations in a field journal. Questions that guided my notes are outlined in Appendix 5. I also made notes if there was anything unexpected or surprising to me. The notes made throughout the participant observations, the audio-taped text, and the entries in the field journal were integrated into analysis. Participant observations ranged from a couple of hours to a full day (7am to 6pm).

Table 4 outlines the specific dates of interviews and participant observations with informants.

Name	Interviews	Participant observations	Additional information
Julia	15. 03. 2011 13. 04. 2011	21. 03. 2011	
Erika	31. 01. 2011 09. 03. 2011	08. 02. 2011 15. 02. 2011	
Veronika	28. 04. 2011 06. 05. 2011 (Phone) 18. 05. 2011	Veronika's mother-in-law was in terminal stage of cancer and cared for at home; as her condition became worse over the course of the study and increasingly mobile professional care-givers became involved into the care of her mother-in-law, Veronika and her husband decided that they do not want to have an additional person around;	
Lisa	15. 03. 2011 09. 05. 2011	23. 03. 2011	Lisa's partner did not feel comfortable in participant observations taking place at their home.
Marissa	19. 08. 2010	Marissa was willing to engage in an interview as she considered the topic worthwhile, however, did not want to engage in any participant observation or further interview.	
Katharina	20. 07. 2010 08. 08. 2010	02. 08. 2010	
Anna	01. 02. 2011	14. 02. 2011 11. 03. 2011	

Table 4: Track of interviews and participant observations

As outlined in the previous chapter, texts are integral in institutional ethnography to display how the consciousness of people at a particular work setting is coordinated to those of other people at various sites elsewhere.

Texts

The objective of including texts into institutional ethnography is to disclose how texts mediate the localities of individuals' daily lives to trans-locally organized practices (Smith 2006). Hence, active texts, that is, texts that are taken up, read, filled in, etc. are relevant for explicating the ruling relations.

Various approaches have been used to integrate texts into institutional ethnography. I am referring in particular to two specific approaches (Smith, 2006): One approach is to investigate texts in regard to how they coordinate sequences of action and are themselves "a sequence in time, a course of action" (p. 67); and the other approach is to investigate an intertextual hierarchy, that is, how higher-order or regulatory texts coordinate texts that directly enter the organization of work at various sites. Both approaches were used to get a thorough understanding of the textually-mediated relations coordinating women's work.

For data collection, this implied that notes about any texts that were mentioned explicitly or implicitly by informants throughout interviews or participant observations were made and texts were followed up (DeVault & McCoy, 2002). If reference to texts was given implicitly, I asked the informants specifically about such texts or how they come to know about what they were talking about. Texts which informants were engaged with throughout participant observations were included upon their consent. In the process of reviewing the texts and trying to get an understanding of how texts are related and mediate the women's work, further texts were sometimes identified to get a more comprehensive understanding of the ruling relations. For instance, in a form that had to be filled in by one informant at her visit to the labor market office, reference was given continuously to the General Business Conditions of the office, thus, the respective text was looked up as well. Table 5 outlines the texts that were eventually included into analysis, along with related and/ or higher order texts.

Texts included into analysis	Related texts and/ or higher order texts
Hospital records	
Information letter about drugs and consent form	
Consultation Agreement with labor market office	General Business Condition of labor market office Public law of insurance of the unemployed Public law for labor market service
Yearly notification about continuation of invalidity pension	General law of social insurance General law of pension
Texts about historical development of disability policies	

Table 5: Main texts included in analytical description

This table does not include texts that I had collected and read throughout the course of the study, but considered not as relevant for the analytical description: for instance, one informant gave me a handbook about the church community of which she is member, or another informant brought print-outs with her about reports that she read on the internet.

4.4.5 Analytical description

Institutional ethnography aims to explicate, to map out, how the everyday life of women with rheumatoid arthritis is put together. Thus, the aim of the inquiry is to provide an analytical description that indicates that the focus is on the observed, on what are people actually doing, and how are the activities of various people are coordinated (Smith, 1990b). Only a limited amount of literature has been published so far on how to approach such an analytical description in institutional ethnography. Townsend (1998) has suggested three steps. These steps include describing what is going on in the everyday, tracing of social processes, and subsequently displaying the ideological character of these processes. Other institutional ethnographers have provided particular recommendations on the incorporation of experience (Campbell, 2006), interview data (McCoy, 2006), and

texts (Turner, 2006) into the analytical description. In this study I drew upon these references as well as upon discussions with Dorothy Smith and Susan Turner (Smith & Turner, 2011b).

The analysis was conducted simultaneously with and beyond data collection. As data collection was going on, I read the transcriptions from interviews and the notes from participant observations inductively. Inductive reading means that I repeatedly read and listened to the data from each woman respectively and tried to get an understanding of the work that women are actually doing, as well as how, where, and with whom does the work happen. If any reference to texts was given implicitly or explicitly, I made notes to follow them up or I would follow up with the informant in the subsequent meeting about the respective text. My understandings and first analytical ideas that evolved out of this inductive reading were shared and discussed with the respective woman if another meeting was still scheduled.

Once data from all seven informants was collected, I engaged further in back and forth reading of my notes and the transcript. Subsequently, I started to group sequences of everyday practices and work done by the women. This grouping was based on their actual work. The mind maps and discussions with the informants about their respective maps were very valuable at this point. Texts that have been pointed out by informants were reviewed back and forth with the various groups to further understand which texts are mediating what informants are doing. Texts are integrated into institutional ethnography to discover how they coordinate what individuals do in their daily lives to extra-locally organized practices, as well as how the consciousness of individuals locally is coordinated to those of others across time and place. This process requires extended periods of reading, thinking, and reflecting on how these different types of texts may relate to each other (Townsend, 1998). Texts were mapped as they occurred as a course of action, as well as how they were related to the actual activities of individuals, and how they may relate to higher order texts (Smith & Turner, 2011a; Turner, 2006).

Throughout the entire analysis a draft of Figure 2 was next to the transcripts and my notes so I was constantly reminded of the problematic of this study. This was very helpful to

not digress into looking at the data from my perspective as an occupational therapist, or interpreting what the meaning is of what the women are doing. Rather, this figure ensured that I kept in focus the work that the women did in going about their daily lives and how their doings are situated within the social relations. Throughout this process, Figure 2 was edited and revised and evolved as the social relations did become more and more visible and clear. Furthermore, throughout the analytical description various institutional ethnographies have been read and reviewed to understand how other institutional ethnographers have transformed the conceptual framework into their research. Reference is made to these institutional ethnographies throughout the analytical description provided in the following chapters.

4.4.6 Ethical considerations

For qualitative research, Guillemin and Gillam (2004) have outlined two dimensions of ethics that are particularly important: first, procedural ethics that refers basically to the approval of respective Research Ethics Board; and secondly, “ethics in practice”, that is, ethical considerations throughout the research process. Both dimensions have been considered in this study and are addressed in the following sections.

Procedural ethics

Ethical approval for this study was given by the Medical University of Vienna in Austria as women were recruited from the Department of Rheumatology from this university. Furthermore, ethical approval was granted by The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) given that this research was conducted as a requirement of my doctoral studies at The University of Western Ontario. The Ethics Approval notice from HSREB of The University of Western Ontario is depicted in Appendix 6. Individuals interested in the study have been informed about the study verbally and in written form. Participation was voluntary and informants could withdraw from this study at any point in time. Any individual who decided to participate in this study had to provide written informed consent. The German information letter and informed consent form were translated into English (Appendix 7). Some of the wording in the letter and form may not exactly meet

the HSREB guidelines; however, HSREB accepted the language as it met the standards of REB at the Medical University of Vienna and no participant was recruited in Canada. For instance, HSREB would have asked for a lay term or description of 'occupation'. 'Occupation', however, was translated into "Alltagsbetätigung" in the German documents. Unlike the English term occupation 'Alltagsbetätigung' does not inherently direct to productive work, but captures well the intent of this study and is a lay term. Hence, no descriptions were added in the German version of the information letter.

Ethnographic research, however, is not following a linear predictable process. For instance the amount of time spent with each informant and the places where time is spent together, in particular in reference to the participant observations, was discussed with each informant respectively and depended on what they were comfortable with. Thus, in addition to the procedural consent, process consent was applied (Murphy & Dingwall, 2007).

Ethical considerations throughout the process

Process consent was sought at the end and beginning of each meeting. At the end of each meeting (either initial interview or participant observation), informants were asked whether they are willing to be accompanied in their daily lives at a time and place that they are comfortable with. Some informants wanted to discuss this with their partner first. In such instances, I would follow-up with the respective woman a few days later to discuss the possibility of another meeting at a place and time of their comfort and convenience. Some informants did not want to meet at their homes, but were happy to meet elsewhere or to be accompanied as they had to attend various appointments or run some errands.

Additionally, at the beginning of each meeting verbal consent was sought. Seeking process consent is in line with the relational and sequential process of ethnographic research (Murphy & Dingwall, 2007). This consent entailed that informants agreed on having me as the researcher present while they may interact with their child/children, partner, and/ or other people with whom they may interact, such as officers at boards,

health care providers, co-workers, or friends. If informants had a one-on-one conversation with somebody, the other person was also asked for his/ her verbal consent.

Informants did not receive any financial reward for their participation in this study; if meetings took place at public cafés, informants' drinks and snacks were paid for so that informants did not have any additional costs due to participation in this study. An example of an ethics in process decision refers to the inclusion criteria; in particular to being the mother of a child that lives at least part-time at home, and of whom the woman has full-custody, based on the woman's self-report. Over the course of the study it became apparent that Katharina's daughter lives with her grandparents who also have custody for her. I discussed with the thesis-committee members how to deal with Katharina's 'deviation' from the inclusion criteria. As her work knowledge and experience may still be shaped and informed by her motherhood, even if the child is not living with her, we decided that Katharina would remain in this study.

4.4.7 Rigor in institutional ethnography

Rigor in institutional ethnography is established through the transparent translation of its conceptual framework into the research design and analytical description (Townsend, 1998). In other forms of qualitative research techniques such as triangulation, member checking, or saturation are recommended for establishing rigor (Lincoln & Guba, 2007; Morrow, 2005; Thurmond, 2001). In institutional ethnography, rigor is not established through techniques used for sampling or analysis but rather through the corrigibility of the maps that are developed of the social relations (DeVault & McCoy, 2006). The notion of corrigibility implies that a thorough analytical description is provided of what is actually happening within the social relations. Such a description is transparent and comprehensible and the institutional ethnographer remains authentic and accurate to what actually happens (Rankin & Campbell, 2006).

Translation

As the data for this study has been collected initially in the German language in Austria, the data was translated into English simultaneously with the analytical description. While qualitative research has been frequently used to provide people whose voices are marginalized in certain contexts with a voice, Temple (2005) has raised for discussion whether translation of people's original accounts into another language is still representing their voices. Such questions have ethical, epistemological, and methodological implications and should not be simply treated and decided upon as technical research matters (Temple, 2008). The issues addressed by Temple (2005; 2008) are based mainly on the impact of translation on narrative analyses within an interpretive paradigm. Thus, questions such as are emotional expressions affected by translation, does it affect interpretation of meanings, and how people perceive them represented are relevant. Concerns about the loss of meaning in qualitative health research due to translation have also been raised by others (Squires, 2008; van Nes, Abma, Jonsson, & Deeg, 2010).

As illustrated in the previous chapter, language is not something being taken for granted in institutional ethnography. However, the emphasis is also not on the meaning or interpretation of spoken or written word. The demand of translation in institutional ethnography lies in the thoroughness and accurateness of the analytical description, so that the social relations, including the language that is taken up in and mediates these relations, are transparent, comprehensible, and accessible to the reader (Smith & Turner, 2011b; personal communication). In this study some of the data was translated word by word to ensure that the advisory committee could enter into analysis. This was done in particular at the beginning of analysis. Subsequently, translation was done simultaneously with the analytical description. Any notes were written down in English and evolving writings were illustrated with comprehensive quotations at first. Any documents and findings discussed amongst committee-members were in English. Thus, their comments and feedback was crucial in ensuring that translations were accurate. If descriptions were not comprehensible, translation was revisited as well as the analytical description itself. One committee-member is German-speaking, and ambiguity in translation was discussed

with her. Furthermore, translation of technical terms was attuned to other literature and also discussed with committee-members throughout the research process.

4.4.8 Presentation of analytical descriptions

The findings of the analytical descriptions based on the research described in this chapter are presented subsequently in chapter five, six, and seven. Each chapter is characterized by a particular analytical focus.

Chapter five provides a comprehensive ethnographical account of the daily work that informants do. In this chapter I drew upon interviews and participant observations.

In chapter six, the analytical focus is specifically about the work setting of arthritis-related health care. The coordinated work of the women and health professionals in producing hospital records is presented. In the textual analysis of hospital records I focused specifically on their character of being “a sequence in time, a course of action” (Smith, 2006, p. 76) Furthermore, the work of the women that extends beyond this work setting into trans-local work settings is explicated as well.

The analytical focus of chapter seven is on different realities that the women have to negotiate and manage in reference to employment, more specifically in reference to employability, invalidity, and disability. In reference to employability and invalidity, the intertextual hierarchy was a particular valuable means for analytical description. Regarding disability, further engagement with the historical development of disability policies was relevant to comprehend the women’s work knowledge. The insights gained from this engagement are also presented in chapter seven.

Chapter 5

5 Ethnographic accounts of the women's daily life

This chapter provides ethnographic accounts of the informants' everyday life. The ethnographic accounts portray the women's daily lives based on interviews and participant observations. The focus of the analytical description in this chapter was on giving an account of what the women who participated in this research actually did as they went about their daily lives, and how their doings were coordinated to the resources available to them as well as to the activities of other people. As such, I drew upon the women's knowledge and experiences gained through interviews and participant observations. This chapter depicts the women's doing to make everyday work visible. The first section contains an analytical description of how the women started the day, how they arranged their place based on their resources and possibilities, how they went about preparing food for the family, and used public and private transport to go from one place to another. In subsequent sections accounts are given of how being a mother, being cared for, and sustaining well-being were accomplished through the work of the women given the actualities, as well as their resources, and possibilities for what they can do and what they actually do in their daily lives. This chapter concludes with a discussion on how the ethnographic accounts that revealed in this research complement existing literature, as well as how the particular focus on the work of Austrian mothers with rheumatoid arthritis furthers the existing knowledge base.

5.1 Getting the work of daily life done

The women described how they went about doing the work of everyday life. The work elaborated on in this section includes work such as getting up and started in the morning, as well as arranging the place based on resources available to the women, as well as preparing food for the family. Furthermore, certain work required going from one place to another. Hence, transportation occurred as relevant in relation to other work that occurred in the informants' daily life and is explored also in this section. The work of the women described in this section is situated within, as well as it informs, shapes, and

emphasizes the organization of the women's work in relation to their respective families. However, the emphasis in this first section is not on mothering per se; the work related to mothering is outlined in the subsequent section in particular.

5.1.1 Getting started in the morning

The women's work goes on night and day. As they get up in the morning, the women do work to get themselves ready for the day, as well as to coordinate their bodily needs and their activities to their family. Katharina has difficulties to get up in the morning. Due to her health condition she described many sleepless nights. Katharina's partner leaves early in the morning, her daughter lives with Katharina's mother, and she herself has only occasional obligations that require her to follow a predetermined time schedule in the morning, so she is able to start the days in her own pace and may sleep longer in the mornings. Anna, in contrast, has to get her sons ready for kindergarten and school in the mornings:

In the morning I get up at around six. I take my medication right away because I cannot walk. The first steps are painful. I cannot balance myself. And then I wake up my children at 6.30 am. I dress the older one as far as I can. Then the father of my children is coming. He helps me, because I cannot do anything, I only prepare a few things. What I can. And he dresses the children and brings them to school. (Anna, 01-02-2011, L 67-83)

In the morning Anna receives support from her mother or the father of her children. As she is aware of her limited abilities and challenges in the mornings, she organizes support to get the children ready for school. Anna was provided with night splints for her hands to reduce the pain in her hands. While the splints reduce her pain during nights, she is hardly able to grasp her blanket or cover her son up with a blanket. It is part of Anna's work to coordinate and negotiate her own needs with those of her children and also with her family. The splints exemplify how Anna has been provided with resources to manage disease-related symptoms, however, these resources are not necessarily enabling her in her doings.

Also Erika has to get up early in the morning to get her kids ready for school. The work of every family member is well coordinated in the mornings and everyone knows what she/ he has to do: getting the breakfast ready, getting the children to have their breakfast,

preparing children's lunch-bags, collecting parents' signatures, and ensuring that the children leave the house on time. Then it becomes quiet in the house and Erika sits down and takes a deep breath. She would continue with taking a relaxed shower and enjoying a cup of coffee afterwards. Erika's husband is at home most of the mornings; however, she is ambivalent about that:

One has to manage a disease, literally. (...) But I have the incredible fortune and the advantage that my husband is – unfortunately – so much at home. That he can do the things in the morning – bringing the kids to school, or seating them around the table for their hot chocolate, because in the morning, I am ... [shows stiff wrist]. I try to compensate for that throughout the day. Honestly I lack the hours between five and nine in the morning. (Erika, 31-01-2011, L238-245)

This quotation illustrates that Erika is on one hand grateful for the tangible support of her husband, and at the same time she would prefer him to be enrolled in regular paid work. Regular paid work would also imply a regular and constant family income which in turn would provide them with more stable financial security than as a freelancer.

When Veronika described how she starts her day, she referred to a recent instance, where she was mowing the lawn the day before in the garden. During the following night she was waking up, could hardly move her hands, and felt still the vibrations in the entire body:

At night, I think it was this entire vibration from the lawn-mower, my motor skills were a little bit shaken up. I was not able to get up properly, and I was really delayed in my movements. And my husband was panicking – what is going on? (...) you know I could still sense these vibrations in the entire body. And somehow I was not able to get out of the bed properly. (...) And I could hardly move my hands up. And my husband said, no, no, continue sleeping. (Veronika, 28-04-2011, L169-184)

The support of Veronika's husband allows her to get decent rest at night so that she is more refreshed in the early morning when the children are waking up, her mother-in-law has to be cared for, the farm-animals have to be fed, and so on. Veronika's account demonstrates how her work is not only coordinated to the doings of others such as her husband, mother-in-law, and children, but also to her own previous and subsequent doings. Also Lisa underscores how her doings are interrelated and coordinated with each other and with others:

Yes, at the beginning [right after the baby was born] I often had breakfast only at 1 or 2 pm, because it did just not work out earlier – at the very beginning. I want to do that differently now. No, I need that for myself and I also get in a hurry, and then I have continuously forgotten to take my medication. I still fight with that now. Because in earlier times, I just had my breakfast and took my medication. (Lisa, 15-03-2011, L355-340)

These accounts exemplify how the work of the informants in the morning is coordinated to the needs of their families as well as their own needs. Their work in the mornings, as well as throughout the day, is happening at actual places and coordinated across time. Informants' homes are the places where they live and spend considerable time throughout the day with their families. As the women's accounts depict, they constantly negotiate their resources in daily life as part of their work. While all informants referred to how they get started in the morning, their doings varied given their abilities, as well as their resources and support available to them. The following examples refer in particular to how informants arrange their places where some of their work happens.

5.1.2 Arranging one's place

Anna is living in a small apartment in Vienna. She has managed to get a washing-machine in their apartment throughout her participation in this study; prior to that she had to use the laundry facilities in the basement of the apartment building. These facilities were only available at certain days and hours throughout the week as they were shared amongst all residents. While Anna is glad that she can do laundry in the apartment, she was pointing to some challenges of having the washing machine in the small apartment and mothering:

Now we have the washing machine in the bathroom. It became tight. Do you know how much this bothers me? Of course because of the disease, I cannot get anything from above or turn around. That is terrible. (...) Yesterday I wanted to give a bath to my children and I have to be there. (...) My mom was here too. The child wants me to wash him. But I am not able to get there. I told him, my hands hurt, I cannot do that. Mummy, granny cannot do this so well, please can you do it? I made it somehow. (...) I am sweating because it is so tight and I am afraid that I could hurt my foot. The disease is so stupid. (Anna, 14-02-2011, L566-589)

Anna describes how she is torn between balancing the disease, carrying for her children, and negotiating the limited space in the apartment. While Anna was already looking for other apartments, she has not yet been able to find one that suits her needs in terms of

being accessible, being near-by her mother, and matching her financial resources. Veronika lives with her husband in his farmhouse and they also made some re-arrangements:

We even reconstructed the bathroom, in the house. The shower, showering chair, a holder, a toilet that is 10 cm higher. Because I told my husband, my knee is also affected and I have issues in getting up. Let's make it higher. And now it is good. (Veronika, 28-04-2011, L664-666)

For Veronika and her husband the adjustments in the house were not a big issue and they made them accordingly. Lisa and her partner are currently planning their new house so that it is accessible. The accounts of Anna, Veronika, and Lisa illustrate their different resources in regard to arranging their homes and how it impacts their work: Anna lives in a small apartment and has to work around the restricted space and her financial resources. In contrast, Veronika lives in a farm-house where she and her husband re-arrange space so that it is most convenient. Lisa, is again in a very different situation than Anna and Veronika, as she and her partner are planning their new house they do account for matters of accessibility already at this point. Despite these differences, all three informants have arranged their places to make their work most convenient given their resources.

5.1.3 Preparing food for the family

Similar to work that has to get done in the morning, also cooking and other housework is accomplished through the women's work. The following accounts of informants exemplify how the social relations in which they are situated make a difference regarding their work. For Anna, preparing food is a challenge; it starts already with getting the groceries done and continues with the cooking. She describes the support of her family as essential for her:

Doing grocery shopping is not possible anymore. Because shopping, somebody has to come with me. I cannot manage that myself at all. I cannot lift a liter of milk. So somebody goes shopping with me and then, I come home, would like to do something, but it doesn't work. I clean up a little bit, watch TV, go to see a doctor, if I have to ... and that's it. Until the children return from school I am alone. If I am doing really worse my mom is here. (...) Because cooking and so on is hard. I cannot lift the pots. How shall I take it? If I would not have the support of my family, then ... I cannot live. Without my parents or husband [sometimes Anna is referring to the father of her children as husband though they

are separated and have never been married] it would be very difficult. (Anna, 01-02-2011, L67-98)

Anna makes her need of the support of her family transparent in this quotation. When Erika is cooking or baking and her husband is at home, she can just call him to help her with cutting carrots, opening cans, or lifting heavy pots out of the cabinet. Erika actually makes decisions about what to cook based on his availability – when her husband is out of the house, she would avoid cooking a big pot of potato-soup due to the peeling and cutting of vegetables and the lifting of the pot. She would like to have a kitchen-machine; however, their family budget does not allow for that. When doing groceries, Erika is very knowledgeable about how much most of the food costs, where to get the best deals; and how you can feed a family of five heads very cost-efficient: Erika describes how she would cook a big meal for lunch so that some of the food would also last for dinner. This way of cooking is very cost-efficient. These descriptions illustrate how Erika's work related to cooking is coordinated with her husband's schedule and their family budget.

Lisa does not have to prepare family meals yet: her son still eats baby-food and her partner eats most of the time in the eatery at his work-place. Aside from that, Lisa is referring to various kitchen gadgets that she is constantly provided by her mother and also other family members such as her aunt: Lisa has a kitchen machine, an electronic orange squeezer, a robotic vacuum-cleaner, and many more things which facilitate her cooking and housework. Additionally, she is strategically planning housework, taking decent breaks, varying occupations that require lots of energy with those that do not; delegating to and splitting housework with her partner. As their apartment is on the third floor without an elevator in the house, Lisa has an 'agreement' with her partner that she would leave heavy groceries, which do not have to go immediately into the freezer and are well wrapped, in front of the car in the basement garage and he would take the things upstairs when he returns home. He is also supporting her with cooking when he is at home. The following quotation by Lisa summarizes well how she has arranged the kitchen and coordinates various kinds of support when cooking:

But I am not putting heavy things up there so that I have to get it down from above the head, because sometimes I have problems there. (...) When I am cooking something with vegetables and my partner is at home, then he is cutting

the vegetables, for instance the carrots. Onions or so are not a problem, but carrots; they are so hard to cut, I don't like that. Or I use the gadget. (Lisa, 15-03-2011, L940-953)

Like Lisa, Marissa has also internalized some practices and the use of gadgets and other strategies to do every day work. For Marissa it almost appears as if she is doing things as she always did:

I do everything exactly as ... I do everything at home. I do vacuum cleaning, I also do some manual work, and I fix things myself. I might need a little bit more strength, or more devices, or so, or ... I don't know, I would put a rag around the pincer, or so ... (Marissa, 19-08-2010, L252-257)

These accounts of informants illustrate that it is not necessarily the performance of a single task or activity that may cause challenges, but rather the constant coordination of various activities and the available resources that support or impede with their work. The variety of resources available to informants shape their work related to cooking and differs as to the time and energy. How resources shape and impact on the doings of the informants in their daily lives becomes also apparent in reference to going from one place to another.

5.1.4 Using transportation

Many things in the informants' daily lives presume or require going from one place to another: for instance doing groceries presumes that the women are going to a grocery store or attending a meeting at any health care or social service office requires them to go from their homes to the respective offices. Transportation was mentioned quite frequently by the mothers who participated in this research. While public transport was the option for some informants, others were used to going by their private car. Katharina and Anna use public transport most of the times. Both women describe the time and effort that is needed to use public transport:

If it is the case – such as in the subway – that the seats are not cushioned, then I have already problems with sitting, because anything that is coming along is affecting the spine. (Katharina, 08-08-2010, L254-260)

I can hardly move on with the public transport. Subway and so on that works somehow; there you can at least go in normally. But with the steps to get onto the bus, that is difficult. Holding yourself. Nobody sees that I am really ill. That somebody would offer me a seat does not work. I have difficulties. (Anna, 01-02-2011, L108-112)

Anna mentions that she is lucky to have currently the support of the father of her children as he is on sick-leave due to some work-injury; he has a car. So if possible she tries to go with him by car. Anna also mentioned that other passengers would not necessarily offer her a seat on the bus or subway given her relatively young age and the invisibility of the disease. While there are special seats reserved and signed for elderly people and people with disabilities, Anna is middle aged and does not look disabled. Katharina was pointing out how challenging it is to coordinate various appointments by public transport, such as the doctor-appointments, appointments at the labor market office or appointments at the social insurance institute. Katharina acknowledges that the challenge is not the train schedules or frequency of trains, but rather, as she was underscoring in the quotation above, being on public transport may have an impact on her body.

Lisa and her partner bought a new car shortly before Lisa participated in this study. She pointed out that the seat-belts of the old car were rather tight. Hence, fastening the seat-belt required additional force to fasten, which in turn affected her joints. Along the same lines, she gave also reference to one of her previous cars that did not have power assisted steering. Julia got a new car shortly after her daughter was born. Initially, when her daughter was born, they had a smaller one which made it challenging for her to lift all the baby-stuff in the car. Now with the new and more spacious car, she experiences a big relief. Much of the women's work described so far is coordinated to or intended to satisfy the needs of their families or get duties done. The examples provide insights into how transportation is one resource that impacts on the daily lives of women with rheumatoid arthritis. Depending on the resources related to transport available to the women, they have to manage various challenges, such as seating on not cushioned seats in public transport or fastening tight seat-belts and lifting various things into the care when using a private car. Despite the variations, the intent of the women in spending time and effort of using transport is to go from one place to another. The women also pointed out that being a mother implies additional travel: such as attending doctor visits with the child, doing

fun-things with the children, attending meetings in kindergarten or school, giving them rides to sport, music, or other lessons in the afternoon, and so on. Thus, as a mother the need for using transport increases and may become also more demanding given all the stuff that one has to bring for the child, such as a buggy, their toys, as well as food and clothes for the child.

5.2 Being a mother

In this section ethnographic accounts of the informants' daily lives are presented with particular reference to their mothering. Being a mother may entail work of negotiating various resources and social relations given the context in which the women are situated. In the following quotation, Julia made very explicit that having children is very meaningful to her and she would not easily have given up her desire:

But I know, I would always regret it. (...) it was always my desire to have two children. And to abandon a child just because I am ill, and abandon it for my entire life, is this worth it? I rather take into account that I have another flare after giving birth and that I am doing worse, than having no child. (Julia, 21-03-2011, L59-66)

The intent of having children becomes very clear when Julia is talking, as well as the time that she spends in thinking and reflecting about having children. Like Julia, Veronika and Lisa also pointed out how it has been always very significant for them to have children. Veronika has experienced two miscarriages and she enjoys now any second with her two children. Lisa is also very happy about being a mother and wants to have another child as being a mother and being a family is important to her. The only reason that would dissuade Julia and Lisa from becoming pregnant a second time would be if their disease would have a clear impact on the baby.

Carrying for a new-born

Julia's and Lisa's children are also in similar age and both recall the times after the children were born quite vividly; especially in regard to how they tried to negotiate their disease with mothering. Julia always wanted to breastfeed her child and so she did. Shortly after giving birth, however, she experienced a severe flare. This situation made

her think differently about breastfeeding, in particular in forethought of having a second baby:

Well, I insisted or I just wanted to breastfeed. And I did it just too long. Well, I had a really severe flare after giving birth and I was doing really badly. [name of baby] did not even have 2.5 kilograms and I had sometimes problems holding her. Or at the diaper changing table – I think I did not change her diapers once at this table, because I was just not able to stand for this time span at the diaper changing table. And getting into and out of the shower was catastrophic. We are planning now a second child, I am currently reducing my medication, and I know exactly, when I do have a second child, well, I say it immediately that right after giving birth I want to continue with the medication again to prevent a flare; so that it does not become as severe again. And the baby will also grow up with the baby bottle. (Julia, 24-02-2011, L179-189)

Julia continues talking about how she negotiated her work and mothering back then. Her work knowledge that she gained during this time would make her do things differently in the future. She believes that she would have been able to cuddle and engage more with her daughter if she would have taken the medication and abandoned breastfeeding. In contrast to Julia, Lisa prepared herself already throughout the pregnancy that she would not be able to breastfeed and eventually she was not. For Lisa it required quite some effort to speak up over and over again against the strong image of “a good mother is breastfeeding her child” as Lisa named it:

I really informed myself a lot about breastfeeding. Yes and then I asked whether it is possible or not. The physicians recommended me basically not to do it. Yes, and that was decisive, I guess. And I think that’s why it did not work out after all because I had it in my mind this way: Well, I have the disease, I take medication, and I cannot breastfeed. And then I was told you can still try it. [right after giving birth by the nurses/ midwives] (...) But I have had it already so engrained in my mind. That is just not for me. I also have talked with girlfriends ahead of time so that nobody would say then, Oh, you are not breastfeeding? I prepared that all somehow. No, I am taking medication and after all it is great that I can get a child, but with breastfeeding it won’t work. I had already prepared everything like this in my mind. Whereby when you are on the go, there is always somebody asking ... and then I say No I am not breastfeeding! and the first thing I say then is, I am taking medication. Because there is this pressure coming from outside “good mother is breastfeeding”. Really, everywhere! That was also the case at the department of gynecology. They cajole you into breastfeeding ... That will work, and try it again, and yes ... yes, I had already a really red breast, due to the entire pumping, breast pump, everything was already really hurting. And inside myself I was just wishing that she [referring to the personnel at the department] is saying it

is not going to work. I was not brave enough to say it. Because then, there is such a pressure. And anywhere you go, the first question is ... He is breastfed in any case, right? He is fed with mother milk? Always! There is never the question or choice Is he getting mother milk or the baby bottle? And then you have to say always No. (Lisa, 15-03-2011, L768-788)

Lisa is delineating very vividly in this quotation the work that she was doing to resist the strong image of “good mother is breastfeeding” that she experiences around her. She collected information, made decisions for her, prepared herself mentally, talked with friends about her not being able to breastfeed to avoid unpleasant questions later on, went through the pain as she felt not brave enough to resist what hospital staff wanted her to do, and eventually she also describes how she had to continuously negotiate the public pressure about breast feeding. All the work that Lisa is describing here is part of negotiating her disease and being a “good” mother. Lisa was referring to companies which sell baby-food, and advertise that if breastfeeding is not going to work, their product is the second best choice. Given her background as a health professional, Lisa was also mentioning that she experiences even more responsibility to breastfeed and spends lots of time and effort to resist the strong image of breastfeeding. Julia’s and Lisa’s accounts illustrate that becoming and being a mother does not only include the actualities of mothering in the everyday life, but also considerations and negotiations about becoming a mother and being a ‘good’ mother.

Getting the children dressed

Some of the struggles and the varying ways of how women manage their work become transparent in Anna’s and Lisa’s elaborations on dressing their children:

It is really terrible when you have small children. (...) The older one, he doesn’t want to dress himself in the morning. And my fingers hurt, the hands hurt. He wants me to put him on his socks. I am not able to do so. I do the jogging pants – that I can do. But the other things. Mom, I don’t want this. I say, You don’t want this, and I am not able to do that. We have had discussions in the morning. Mom, I do have an exam today, please, can you put on my socks? That was the best, he is kind. I say, it doesn’t matter, exam and socks – both you have to do yourself. (Anna, 11-03-2011, L262-269)

I just did not dress him with the tightest things that was horrible to get into it with my fingers, I just dressed him wider clothes such as that (pointing to her son's clothes). Such things helped me. (Lisa, 15-03-2011, L602-606)

Lisa decided that she would use the clothes that she was able to dress her son with based on her abilities. It did not cause her any difficulties, and in contrast to Anna, it was not severely interfering with her work. Anna's children are older and able to partner with her in some regards, while overall they still ask for her care and mothering. This is challenging for Anna at times as the quotation above has illustrated. She is very explicit that the children would like to engage in different activities with her, like going to the mall, play-ground, or eating outside, however, she is not able to do it anymore. Caring for a sick child can become even more challenging. Anna was referring to a situation when her son was sick and required certain medication that was packed in bottles with a particular closure. She was unable to open the bottle. Although she got a device to help her open this particular bottle, the device was stored in the kitchen and she wanted to stay with the child in the living room. Anna states how she was torn between providing the best care to her child as fast as she could while being also challenged herself due to her disease. Anna was pointing out how she is constantly partnering with her children or she tries to engage them in various house chores to make things work in their daily life.

Anna's and Erika's children are of similar age and attend school. Erika and Anna were coordinating their daily schedules around the times when the children would be at home. The times can become quite busy before the children go to school and once they return home. Thus, both were mentioning how they try to get some rest or do something to care for them while the children are at school so that they would be refreshed when the children are around.

5.3 Being cared for

Being a mother means being a care-giver. Informants were also describing consistently throughout all interviews and participant observations how they are cared for. Anna receives a lot of support from her mother. Her mother provides her in particular with tangible support; however, Anna also mentioned that sometimes she would also like to just have a chat with her.

Yes, she is helping me a lot, because she is doing everything for me. She does not have to, but she thinks so. I don't want that she does that. Because I want that my mom is resting too and chats with me. However, she doesn't like that, she doesn't like it. But she is coming any time. She is always available, always here. But then I hardly see her. Then when she has cleaned over there, then I go there and watch TV; I follow her a few steps, I help her a little bit. And then she says immediately, sit down, come on, sit down. (Anna, 11-03-2011, L54-60)

This quotation points to the work that is required in Anna's instance to balance being cared for, receiving the care that you are longing for, along with the needs and values of the person who would care for you. Julia was describing how it was a particular challenge for her to negotiate a tension between doing badly herself due to an acute flare, accepting the care of her partner, and at the same time seeing how he was suffering as she was suffering; and yet, Julia underscores how important it is to be cared for and having somebody that cares for you.

No, it is really important for me. I don't know how I would have managed without, if there would have been nobody when I was so bad. To be really alone with that ... I imagine it to be very difficult. But [name of her partner] was totally sensitive, cautious; but at the same time not pampering me. Certainly, I have found my motivation in him to not let go with me. (Julia, 24-02-2011, L474-480)

Anna's and Julia's example make transparent how caring for family and being cared for by family requires work to balance one's own needs, as well as the needs of the other person, and also to bear that somebody is suffering with and caring for you. In this regard, Lisa is describing how her family could not fully share Lisa's happiness when she informed her parents about her pregnancy as they were concerned about her health:

But it was not so much the concern that I had [she was referring earlier to her concern about the baby's health], but more about the concern about me. (...) Basically they were sitting in my neck to some extent and asked every other day whether everything is okay. Also, when I had an appointment somewhere, they called immediately: "And? Everything alright?" (Lisa, 09-05-2011, L255-276)

Similarly, also Julia was referring to experiences where her family could not fully share her desire for children. She is holding back their plans for the second child as she has experienced previously that not everyone in her family would understand her decision. Erika does not have her parents around like for instance Lisa, but she, her partner and

children are active members of a church community where she receives a lot of support and care as well:

There is mutual help, tangible as well as emotional help, spiritual help – however you want to call it. (...) That there is a network. (...) That is worth of gold. When somebody tells you may see it from a wrong perspective, or just think about this and that, whatever. And you are doing better. Whatever it is or how you want to name it, but I believe strongly that this is very much to our advantage. (Erika, 09-03-2011, L402-427)

Erika has also pointed out how difficult it can be to accept informal care at home as she herself is providing formal care outside the home in her professional role as a health professional. She was addressing the paradox of providing care to others, but then being in need of care by others at home. Anna, Julia, Lisa, and Erika have pointed to how important it is to have somebody around that cares for you and is available, or just knowing that somebody would be available.

5.4 Sustaining well-being

Informants were doing work in their daily lives to sustain health and well-being. In contrast to taking medication as part of informants' morning routines, the examples in this section refer to time and effort that women spend with the intent to do something good for themselves. Some informants, such as Lisa, Veronika, and Erika were referring to how they engage in activities to care for themselves, to do something that makes them feel well. Based on their experiences, they know that their well-being is closely interrelated with their disease status:

If I have enough time for me, that I can do things for myself, sleep enough, and care for my well-being – well these things are interrelated – and then I am doing automatically better. (Lisa, 09-05-201, L235-240)

Today I am going to my cosmetician because I do manicure from time to time. (...) I hope that does not sound egocentric. But that is for me - this half of an hour. Or when I am in the shower, at the evening. Everything is quiet around me. In former times showering was done in a second. Now, 15 minutes at least. I need that. I simply need that. That provides me with energy. (Veronika, 18-05-2011, L201-206)

But I do take time for myself. I do that regularly that I take a shower at first before doing anything else. Really extensively. Then, I sit down and drink comfortably my coffee and read something or just take half an hour for me. (Erika, 31-01-2011, L489-493)

All three of them were pointing out how important it is to have this time for them as it contributes to their well-being and provides them with energy. Lisa also provided other examples about the work that she is doing to maintain her well-being by participating in various activities with friends and family. She describes how it can be a challenge to participate in such activities while balancing her disease-related symptoms:

For the past little while I have had a few problems with my joints. It is my own fault. We have had a few birthday parties and the friends made it especially for us in their homes and not in a public pub so that we could also attend. Because then we could bring him [her son] to bed in their bedrooms. And I really enjoyed that – that was something for me, not for my health, but for me. That we have been there and participated in partying, and then we stayed there for quite some time, meaning that I only had little sleep. And that was bad then, because then it is becoming worse. And then I simply demanded from my partner, please take care [of the baby]. (Lisa, 09-05-2011, L213-227)

Lisa also pointed out how these activities that provide her with well-being are coordinated with the activities and work of others: her friends organized the party at home so that both, she and her partner could participate with the baby; and her partner was supporting her so that she could recover afterwards from the lack of sleep. Lisa was also describing how she always felt the risk of falling and hurting herself when skiing which subsequently prevented her from doing it. As her partner and friends are passionate skiers, she has started skiing some years ago so that she can join them.

Julia is a very active person and has always done a lot of sports. She underscored that she is continuing doing sport as she gains a positive effect out of it despite the disease and she always tried to continue participation in sports even if she was not doing well regarding disease-related symptoms:

But I continued to go to the sports lessons just as I was used to. I mean, I was not able to do a lot at all. I was still able to run and to jump into the mini-trampoline, and make somersaults. I did not do the handstand, but I did everything else with the wrists and sometimes it happened that I twisted my joint – that all the pressure that was put on it ... and then I was lying in the hall out of pain, because everything did just hurt. But despite of it all, I still had my sport, and I was ... (...) at the beginning I went five times a week, about 4 to 5 times a week. That

was always the same group and somehow I was outside the group as I was not able to go there. Just for my feeling. Most likely from their perspective not, but I felt that way. They are always going for a drink afterwards and come together; it has always been cozy and (...). That was just the circle of friends, the sports hall. (Julia, 14-03-2011, L322-339).

Julia described how she put lots of effort into continuing going to sports that provided her with well-being and ensured social participation. As these examples from Lisa and Julia illustrate, negotiating health and well-being may imply that women engage in things that would compromise their disease-related symptoms, such that it increases pain, but provides them simultaneously with well-being.

5.5 Discussion

The ethnographic accounts presented in this chapter illustrated how informants' work takes place in the actualities of daily life, namely at actual places, real time, by and with real people. All informants are situated within varying social relations. Their social situatedness offers varying tangible, economic, personal, and social resources that have direct and indirect impact on the work of the women in their daily lives. Their emotional resources and family relations came inevitably into view in discussions about their work. These findings support and are supported by the current knowledge base about the daily lives of women, and in particular mothers, with rheumatoid arthritis. These findings also complement the knowledge base by taking the social context of the mothers into consideration, and addressing how this context is actually shaping the doings of the women in the actualities of their everyday life. As the quotations and descriptions in this chapter demonstrated, while the intent of the women is to engage in particular activities, the effort and time required to do so is influenced by their resources given their situatedness within the context. For instance, all informants referred to mothering, cooking, or caring for their children and families; however, the actualities of these activities, the time and effort required, and how the doings are coordinated to the activities of others varies across women. Thus, in this remaining section of this chapter, I reflect on the findings mainly in reference to some of the literature reviewed in chapter two and outline how this research complements and furthers the existing knowledge base.

In this research all informants referred to how they receive support primarily from their partners and immediate families as they prepare food for the family and care for their children. It remained unquestioned that the women performed these activities. Veronika underscored that she does not want to sound egocentric when occasionally taking time to go for manicure; Erika stated that it is a challenge for her to accept tangible support at home as she provides care and support to others as part of her part-time employment. Negotiating support also contained for Julia and Lisa the work of moderating their parents in their efforts to provide them continuously with appointments for and information about complementary treatment. Similarly to the findings by Goodacre and Goodacre (2003) and Nyman and Larsson Lund (2007), the women in this study were negotiating support by and with significant persons. Grant (2001) highlighted that in particular for mothers with rheumatoid arthritis receiving support can become a challenge if the mothers find themselves within a traditional, conservative context. While the participants in the study by Grant (2001) referred in particular to support offered by the women's partners, this research has also pointed out that social relations informing support are very complex and include the support of the own family and family-in-law, and goes beyond tangible and emotional support. This institutional ethnography disclosed the time, effort, and intent that go into negotiating support and care if support becomes for instance too overwhelming.

The literature specifically on mothers with rheumatoid arthritis pointed to the continuous and yet changing challenges when being a mother with rheumatoid arthritis (Backman, Del Fabro Smith, et al., 2007; Barlow et al., 1999; Del Fabro Smith et al., 2011; Katz et al., 2003). The ethnographic accounts of informants in this research support these continuous challenges: the children of Lisa, Julia, and Veronika are of similar age. The three mothers referred to challenges in relation to for instance breastfeeding and dressing the children. The children of Erika and Katharina were already of school-age; both mothers underscored the challenges in getting them ready for school in the morning and being fully available for them after school. The times prior to and after school are intense and demanding at times as the two informants highlighted. While not specifically to rheumatoid arthritis but to mothers with chronic illness more in general, Opacich and Savage (2004) highlighted that not only do the challenges of being a mother with a

chronic illness have to be considered, but also factors that may increase or decrease the women's well-being and quality of life. In literature specific to rheumatoid arthritis, mothers referred to mothering as being a very significant part of their life (Del Fabro Smith et al., 2011). Similarly, in this research some of the women highlighted that mothering is very significant for them: Lisa and Julia would only abandon motherhood if their disease would interfere with the health of the child; also, Marissa and Veronika highlighted the joy that their child/ children brings into their life. Except Katharina, all women emphasized that becoming and being a mother impacted on their priorities: the health and well-being of their children became priority over their own.

These negotiations of the women illustrate the social norms and expectations that shape the daily lives of mothers within the Austrian context. Leitner (2003) has referred to the Austrian context as being informed by social policies that are grounded within an explicit familialism. The ethnographic account of this research illustrated the actual work done by women within their daily lives within such context. How informants were describing and living their daily lives did not question these expectations, but rather illustrated the normality of these expectations and the efforts and time needed and spent to live up to these expectations.

The ethnographic accounts outlined in this chapter provide a thick description of the work that women do in their daily lives, and how their daily life becomes accomplished given their abilities, resources, and actualities of everyday life. These findings illustrate the situated nature in which the women's doings occur. Most of the informants were hardly referring to disease-specific symptoms, but rather how they are able to manage their everyday lives and ensure that they experience well-being in doing so. Based on the account of informants' daily lives, I aimed then to explore the disjuncture between the women's daily lives and arthritis-related health care.

Chapter 6

6 The ruling power of arthritis-related health care

This chapter provides an analytical description of the organization of the work within arthritis-related health care. I drew in this chapter on the women's experiences and work knowledge of receiving treatment in this setting. In addition, my knowledge as a professional having worked in this setting informed the analytical description and allowed for a more comprehensive picture of how the work of the women is coordinated with the work of others also active in this setting and beyond. The focus of the analytical description in this chapter is on mapping out the social organization of the textual production of hospital records along with an ethnographic description of the work that allows for this production to occur within the setting of arthritis-related health care. In the textual analysis of the hospital records I drew in particular upon the idea of texts as coordinating sequences of action and being themselves "a sequence in time, a course of action" (Smith, 2006, p. 67).

In this chapter I outline in the first part the work setting, to subsequently illustrate how hospital records become produced through the coordinated work of various people and at the same time coordinate various sequences of action within this work setting. Then, I outline the work that informants are doing in and beyond this work setting, and how their work is coordinated to the organizational processes in this work setting. This chapter concludes with a discussion on how the women's work as patients with rheumatoid arthritis, along with their unique resources and needs, fits into the work setting of arthritis-related health care and becomes accounted for.

6.1 The work setting of arthritis-related health care

The work setting of arthritis-related health care is at the outpatient clinic at the Department of Rheumatology in Vienna. This is the work setting from which the women were recruited for this research and where I used to work as an occupational therapist. The analytical description of what actually happens in this setting is relevant for this research to comprehensively understand how women's experiences of their everyday

lives become addressed and accounted for in arthritis-related health care. This analytical description was targeted toward exploring how the work of mothers with rheumatoid arthritis is coordinated to arthritis-related health care. This exploration was a significant part of my interest in understanding how the disjuncture between arthritis-related health care and the complexity of women's daily lives might become accomplished given the social organization of this work setting. The interconnection between women's everyday lives and arthritis-related health care happens for informants in particular at this work setting as they return to this setting regularly for routine visits. My experience of having been part of the team of biometricians was an important resource in analytically describing the organization of this work setting along with the experiences that informants were describing. Biometrician refers to a team of health professionals at the department (e.g. occupational therapists, physiotherapists, nurses, and psychologists) that is responsible for conducting various routine and research-specific assessments and evaluation at the clinic. In this first section I briefly describe the work setting and delineate the organizational processes of a routine visit in this setting.

Given the structure of the Austrian health care system (see Chapter 1), an outpatient clinic attached to a public hospital is regulated under the state law and implies that services offered at this clinic are not offered elsewhere or within reasonable distance for patients (RIS, 2011). Marissa, Katharina, Lisa, Julia, and Veronika used to live in Vienna but moved at some point to more rural areas outside Vienna that belong already to another province. They still return to the outpatient clinic for routine visits as they acknowledge the expertise at the clinic. As access to health care in Austria is not regulated geographically, their return to the clinic does not constitute a problem in institutional or organizational terms although they live in another province now.

The Department of Rheumatology is coordinated to the Clinic of Internal Medicine which is an organizational unit of the Medical University. The clinic is located in the General public hospital of Vienna which represents the clinic center of the Medical University. Thus, many students from the Medical University conduct their internships or specialist trainings at various clinics and departments within the hospital. Trainees would stay at one department for some time and then rotate to another department. This organizational

process may imply that a patient sees a different doctor any time when she comes to the clinic. Some informants pointed implicitly to this organizational process as illustrated in this chapter (see 6.3.1, Authoritative knowledge); or explicitly, as for instance, Lisa who highlighted that she does not appreciate the changes in attending physicians. She states further though that “at least I have the feeling at the clinic that one is at the latest state of knowledge ... well that is how it is at a university clinic” (09-05-2011, L 469-489). Erika acknowledged the comprehensive evaluation of her health status that she was not used to from other clinics:

“they have done things at the clinic that nobody else did before, such as ultrasound, or the assessment of the biometrician or such things; nobody else did ever palpate my joints before, nobody” (Erika, 09-03-2011, L 167-175).

I focused in this research on routine visits to the outpatient clinic to disclose how the complexity and continuous changes and challenges of daily life become accounted for or met in arthritis-related health care, or alternatively remain unattended or excluded. Figure 1 depicts the work that goes on in the work setting at this outpatient clinic at a routine-visit of the women. The lower dark-grey box illustrates the work that is done by the women; the upper light-grey box outlines the work done by the health professionals. The significance of the hospital records in coordinating the work that goes on at the clinic becomes apparent in particular in this upper box. The work of various health professionals and the women is coordinated as the curved black line depicts. The arrows on the left and right bottom of the figure show that this is a sequence in time as work is happening before and after. For instance, before the receptionist pulls out the health care record, the woman has to register for her visit. To register means that she is providing the receptionist her electronic health card. The application of the electronic health card serves as a proof of the woman’s insurance status and is essential for the settlement of her health care costs (BMASK, 2010b).

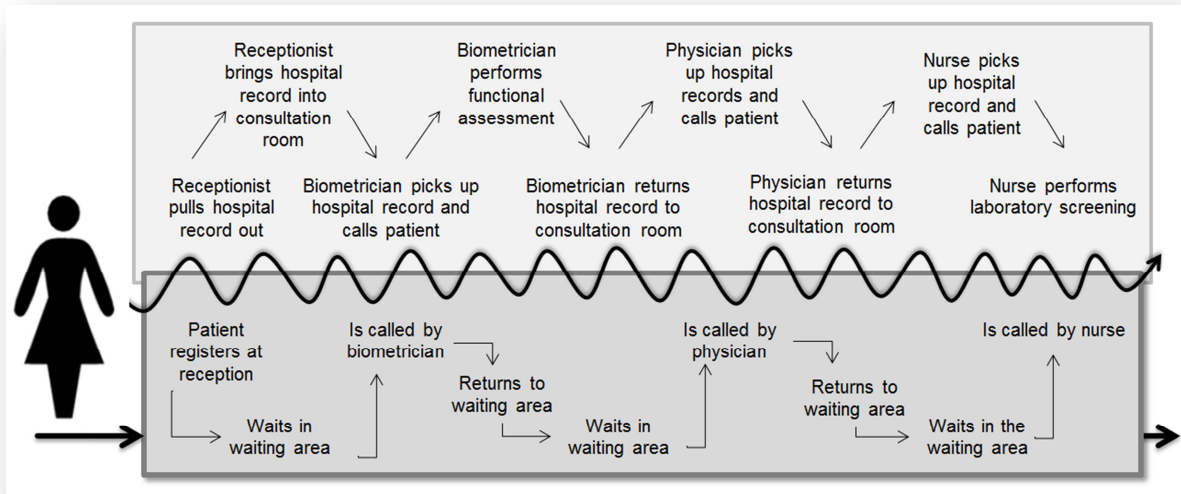


Figure 3: Processes of a routine visit in arthritis-related health care¹⁶

Texts, such as the hospital records, mediate in and between local and trans-local work settings. Thus, I explored further the work of and mapped out the social organization that goes into producing hospital records within this particular work setting in the following section.

6.2 The organization of the production of hospital records

The hospital record itself is a material form that has a replicable and mediating character. The hospital records that informed the analytical description are hospital records of informants that were used in the clinical setting – an actual, observable, local setting within public health care in Austria. The focus in this section is in particular on the work done by for instance the receptionist, the biometrician, the physician, and the nurse as illustrated in the upper box in Figure 3. The women's work and how their work is coordinated to the work of professionals are further explored in section 6.3, The ruling of the women's work in the setting. The work of these professionals is organized in a particular structure, which allows for the production of the hospital records. This

¹⁶ Figure 3 was developed within the scope of this dissertation.

structure becomes accomplished as each health professional does the work and gathers the information that is supposed to go into the hospital records. Most of the information that goes into the hospital records is written down and recorded within this actual work setting while the actual work has happened already or will happen trans-locally. For instance reference might be given to a previously made assessment or to a screening that has to be made in the future. Hospital records in this work setting locate a collection of texts that are ordered in a particular way (Figure 4).

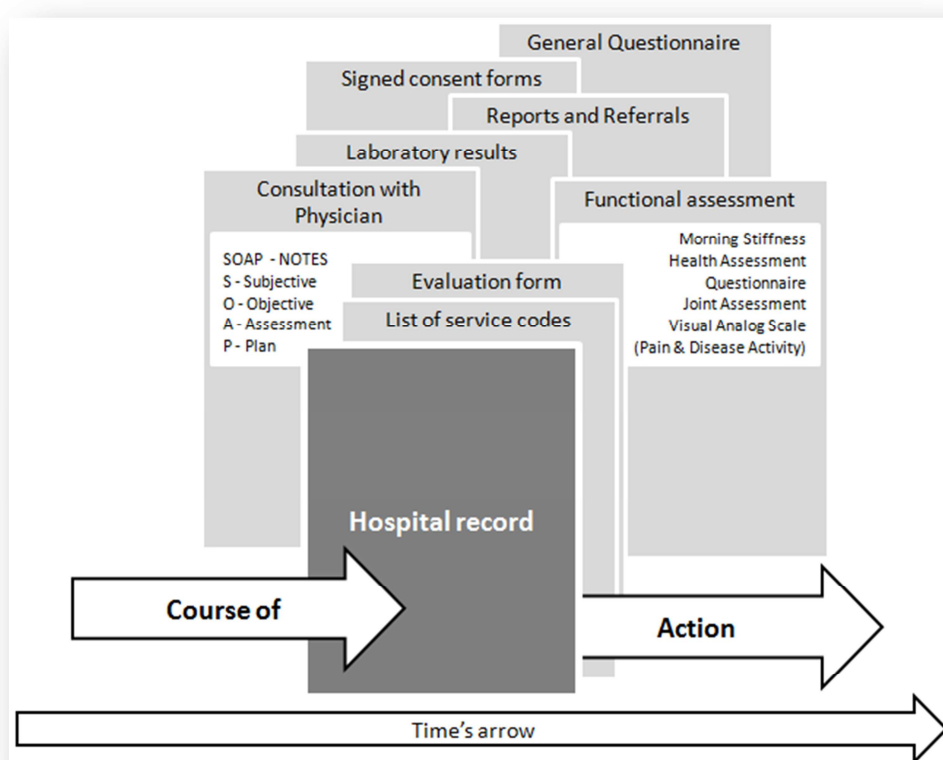


Figure 4: The coordinated work of producing hospital records¹⁷

Each part of this structure opens up again a compilation of other documents. In this chapter only the parts which were relevant for exploring the organization of the coordination of the women's work, their daily lives, and arthritis-related health care in

¹⁷ Figure 4 was developed within the scope of this dissertation.

this work setting, are further analytically described. The List of service codes (Figure 5) outlines various services along with codes assigned to each service. This list is followed by columns where each individual that performs any of these services is supposed to put her/ his initials and the date. As soon as a health professional puts her/ his initials next to the service code, the respective service would become accountable for settlement once it is entered into the settlement system by somebody else in the administrative office.

4213	Talk with physician			
4652	Outpatient talk with physician – 15 min			
7762	Erythrocyte sedimentation rate			
...				
4945	Injection			
8710	Ultrasound of the joints			
...				
1498	Functional status			
...				
5496	Occupational therapy – functional training			
...				

Figure 5: Illustration of List of service codes¹⁸

The Evaluation form (Figure 6) provides precise instructions about the content of a routine visit to the clinic of patients with rheumatoid arthritis, namely the frequency of each service and the professional who is responsible for the respective service to be conducted. Thus, the Evaluation form authorizes the work that gets done and by whom, as well as the frequency of the work.

¹⁸ Figure 5 was developed within the scope of this dissertation based on the content and structure of the List of service codes (in German language) in informants' hospital records.

												Please check if applicable FA / SFA
Date (first visit or rather date last done)												
Every three months or when change of basic treatment												
Physician's assessment	Physician											
Rheumatoid arthritis assessment	Biometrician											
Control II and ESR	Nurse											
First visit, afterwards on a yearly basis												
X-Ray of Skeleton	At least hands, forefeet, spine											
In case of additional FA or SFA, then:												
...												
In case of additional Osteoporosis, then:												
...												
FA=Early arthritis: Symptoms <3 months; SFA=Late Early Arthritis: Symptoms >3 months <12 months												

Figure 6: Illustration of Evaluation form¹⁹

The List of service codes and the Evaluation form, as well as other texts in the hospital records are coordinated to each other as mapped out in Figure 7. The bold black arrows illustrate how services that are outlined in the List of services are also outlined in the Evaluation form. The fine black arrows exemplify how the services are then linked to the respective sections in the hospital records. Services that are required for the comprehensive evaluation of a patient with rheumatoid arthritis but cannot be conducted at the department due to lack of technical or human resources would be referred to another department. An example therefore is ‘X-Rays of Skeleton’ which is listed at the Evaluation form as being required on a yearly basis. The referrals to and reports from the other departments are filed in the hospital records too.

¹⁹ Figure 6 was developed within the scope of this dissertation based on the content and structure of the Evaluation Form (in German language) in informants’ hospital records.

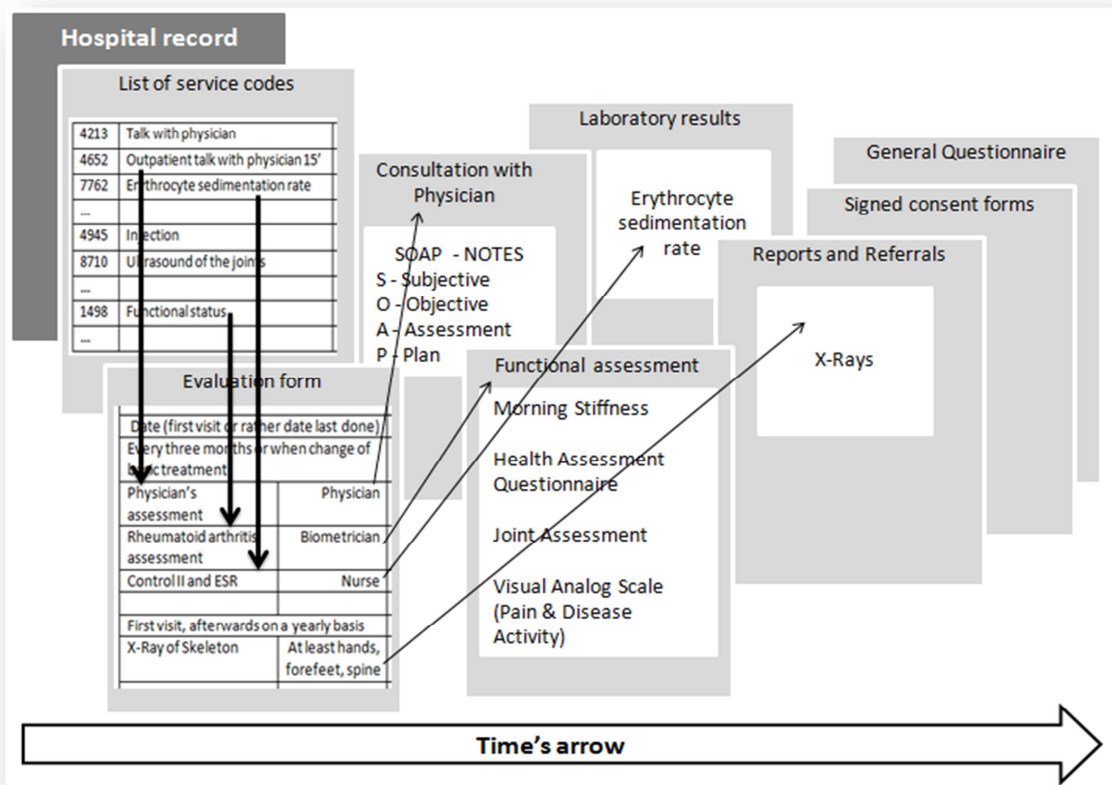


Figure 7: Coordination of texts within the hospital records²⁰

The subsequent paragraphs are focusing in particular on the work that is done in conjunction of the biometrician, the physician, and the patient: the biometrician conducts functional and health-related assessments of the patient at every routine visit, and the physician monitors the disease process and bears responsibility for any treatment decisions. Thus, these professionals occur as particularly crucial in exploring the disjuncture of everyday life and arthritis-related health care.

²⁰ Figure 7 was developed within the scope of this dissertation based on the content and structure of informants' hospital records.

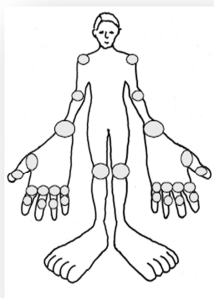


Figure 8: Documentation form for joint assessment²¹

The assessment of the biometrician contains a standardized joint assessment of swollen and tender joints. Any joint that would be swollen and/ or tender would be check-marked in a form as depicted in Figure 8.

The further assessment of the biometrician covers a record of the patient's morning stiffness in the joints, which becomes documented in minutes. Then the patient is asked to mark on a Visual Analog Scale (VAS) from 0 to 100 her pain and disease activity respectively. A third VAS is completed by the biometrician who also rates the disease activity (DA) of the patient. The outcomes of these three measurements are evaluated by the biometrician and also written down in abbreviated form in the hospital records (Score of VAS pain/ Patient-Score of VAS DA/ Biometrician-Score of VAS DA; e.g. 0/2/12). The biometrician asks the patient also to complete the Health Assessment Questionnaire – Disability Index (HAQ-DI), calculates, and documents the score. The HAQ-DI consists of eight categories, namely dressing and grooming, arising, eating, walking, hygiene, reach, grip, and common daily activities.

The analysis of the hospital records revealed that at some instances the biometricians made notes about additional information in the records, such as “Patient is helpless; severe pain” (Katharina, 06/2008); “Patient still symptoms in left wrist” (Katharina, 01/2009); “Patient reports severe pain in entire body” (Katharina, 11/2010); “on both hands large-area swelling – close to metacarpophalangeal joint” (Anna,02/2010); “Patient reports pain in both temporomandibular joints” (Anna, 10/2010); “Pain in both shoulders (not pressure responsive); pain in left knee when walking downhill” (Marissa, 03/2010); “overall, once a month a painful joint, other than that no problems” (Lisa, 01/2008); “when reducing medication worse, dose again increased – is actually going better than

²¹Figure 8 has been modified based on a figure taken from <http://www.gp-training.net/rheum/ra.htm>; retrieved on January 10th, 2012.

before dose was reduced” (Lisa, 04/2008). These additional notes referred to symptoms or experiences that patients were talking about but for which no standardized way of reporting is foreseen in the hospital records.

Once the patient is assessed by the biometrician, the patient returns to the waiting room until she is called by the physician. The physician follows the SOAP-structure in his/ her documentation: S – Subjective; O – Objective; A – Assessment; P – Plan. The heading ‘Subjective’ captures notes about the patient’s description of her health status and symptoms. These notes show a broad range of entries, such as: “very good – cleaned the windows the day before” (Marissa, 03/2003); “until last week pretty good – since 3 weeks many personal issues so that intake of [name of drug] was forgotten once; since one week increased swelling, no pain” (Marissa, 01/2004); “it is going; scrubbed floor yesterday thus not so good now” (Marissa, 02/2005); or “baby was born (date), everything is fine; but joints are worse” (Julia, 04/2009); “unchanged swelling and mild arthralgia (fluctuating)” (Julia, 02/2010); “is going well” entry is complemented with a list of current medication and date of latest X-rays (Julia; 04/2011); “currently not so good, lots of stress; status post inpatient treatment due to skin-infection; pain in hands and feet; morning-stiffness about an hour” (Veronika, 09/2003); “since switch in medication to [name of drug] – subjectively significant worse; [list of current medication with respective dose]; patient non vult [does not consent] to participate in any study; non vult [name of drug]” (Veronika, 02/2006); “currently lots of stress; hardly rest; migraine; cold is good, also cold weather” (Veronika; 11/2008); “tired; arthralgia” (Veronika; 02/2010).

Some notes were written down in informants’ lay language; others were likely transformed into technical language or refer already to specific concepts such as the reference to arthralgia, or the listing of medication. The heading ‘objective’ captured mainly a summary statement of previous laboratory results, or a Disease Activity Score (DAS) or a Clinical Disease Activity Index (CDAI). Parts of the results of the functional assessment conducted by the biometrician would be taken up by the physician for the calculation of the DAS or CDAI. The diagnosis is listed under ‘Assessment’; also

pregnancy would be stated there. 'Plan' entails the treatment plan, referrals to further screenings or assessments, and the time-span until the next visit.

In some instances patients were referring to their experiences which are not always taken up in the further treatment plan. For instance, in Marissa's hospital record is an entry dated with November 2007: 'Subjective': "not as good, Pat. did not take medication for past 2 months due to desire of having a child"; under 'Assessment' the diagnosis is put under question mark, subsequently, in the treatment plan a list of additional laboratory assessments is suggested and Marissa is called to a follow-up visit in 8-weeks time. In the subsequent entry in January 2008, it is stated under 'Subjective': is going pretty good, did never take pain-med". The further notes are about the disease activity score, reference is given to an X-ray report, and the diagnosis is stated as "active rheumatoid arthritis". Marissa is informed about an MRI/ sonography study and an appointment is arranged for her. At no instance reference is given to Marissa's desire for a child that was decisive for her to discontinue taking medication previously. The physician continues according to the standardized documentation that coordinates his/ her work to the organizational processes.

Once the patient has consulted with the physician, she would return again to the waiting room until the nurse calls her. The nurse picks up the hospital record and conducts what the physician has stated in the Plan regarding blood screenings. The work of each health professional requires documentation which means the production of further texts that are compiled in the hospital records. These texts are then available for "reading, discussion, and review by people in multiple locations and at certain times" (Turner, 1995, p. 237). The reading, discussion and review of what is written down in the hospital records occurs within a single visit: for instance as the physician draws upon the assessment of the biometrician to calculate scores such as the DAS or CDAI, or the nurse performs screenings that the physician has outlined in the hospital record. Furthermore, the reading, discussion, and review of hospital records occur also across time: any health professional, who is familiar with the organizational processes, can pick up the hospital record of any patient and make sense of what has been written down in the hospital records. Lisa described this standardized processes as follows:

Well and it is so that when one comes into the outpatient clinic and they take the hospital records, look into it, and ... Ahm what has been, ah, that was ... okay, that ... they only have a short overview, because they don't know you. Taking a short view into it, capturing the most important facts at a glance, and then coming to a decision. (Lisa, 09-05-2011, L 469-489)

Except for some notes by the biometrician and physicians' comments under the heading 'Subjective', the language used in the hospital records is conceptual, abstracted from the everyday lives of women, and establishes objectified accounts. All documents and reports that are compiled within the hospital records refer to biomedical concepts, such as diagnostic criteria, medical treatment, functional status, or disease activity. Hospital records accomplish facts as they introduce and subsequently refer back to officiate concepts (Ng, 1995). The concepts as they are interrelated with each other and coordinated to each other inform the institutional discourse that is ruling the health care system. What becomes written down in the hospital records is framed within the boundaries of particular concepts that ensures an efficient and clear communication although people are not talking with each other personally. "People use institutional concepts to communicate efficiently in their work" (Daniel, 2008, p. 256).

This analytical description shows how arthritis-related health care is ruled by concepts and categories that allow for coordinating the work of health professionals and making their work accountable. These concepts and categories are documented in the hospital records, which serve as texts mediating the ruling relations in this work setting. Nevertheless, as the bottom dark-grey box in Figure 3 depicts, the women are also doing work which is coordinated to the work of the professionals.

6.3 The ruling of the women's work in the setting

Much of women's work throughout the clinical visit is waiting (see Figure 3, bottom dark-grey box) while the hospital record is organized, produced, and compiled as the health professionals do their work. Once the woman is called by the biometrician, the physician, or the nurse, part of the informant's work entails responding to questions, engaging in examinations of her joints, and completing for instance the HAQ-DI. At the very first visit, the women fills in a socio-demographic questionnaire that becomes filed at the very end of the hospital record (see Figure 4). This questionnaire contains

questions about her family medical history, medical history of the patient, life habits such as smoking, drinking, and eating, medication intake, and social history of the patient (professional background and status, and marital status). At the end of the questionnaire are two sections: one is supposed to be filled in only by women; the other only by men. Women are asked specific questions about their menstruation, about previous pregnancies and breast feeding; men are asked about urological screenings, whether they experience challenges in their sexual functioning or changes in their sex life. The gender-specific questions indicate that the focus is on the biological sex rather than on the gendered self or gender as a lived reality, for instance no question is asked about fatherhood or about women's sex life.

Much of the work that women are doing happens trans-locally and yet happens in response to or is coordinated to the hospital records. For instance, women do work to ensure that they can attend their routine visits: Lisa pointed out that she wants that her partner is able to do anything with their child – such as feeding him or bringing him to bed – as she is aware that she is away for a day at least every three months when she has her routine visits at the outpatient clinic. Also Veronika was describing the work that she has to do around a particular visit; she has to adjust, arrange, and coordinate her work at home accordingly:

Then I have cooked for today, well I have pre-cooked everything (...) Then I have given the list [a list of things that have to be picked up] to him [referring to her husband] – your brother can go there, because you have to stay with the children, and so on ... I have shown him about the medication and the injection, because she [her mother-in-law] needs another injection. Then the drip, yes, and then we also were talking about – my husband is very knowledgeable about the baby food. Basically he is better in regards to how many cups for how many milliliter of water – that is not a problem (...) Then I went up, went for shower, and prepared everything for the day. Tableau for breakfast, cups, putting on the coffee machine (...) Then I have looked several times at my mother-in-law, because I was thinking, if she would be already awake then I could wash her. Then it would be easier throughout the day. (...) my husband took me to the train already at half past 6. Normally, the train leaves at 7.11 am, but of course – he was afraid, if one of the kids would wake up or the mother wants to get up, then. Yes, and my sister-in-law comes at 8am to help him. (Veronika, 28-04-2011, L 149-201)

As become obvious, Veronika does also a lot of work that is not talked about and not accounted for. Her work, as well as the work of the other informants, remains unnoticed in the hospital records. Marissa was referring to how she coordinates her routine visits with other errands nearby the clinic. She would bring her daughter, as well as food and toys for her daughter. The work for informants however does continue after their routine visit at the clinic. Informants may have to pick up some medication at the pharmacy and go to their general practitioner to receive further or revised prescriptions. Marissa just mentioned in a side-note that she would briefly stop by at the general practitioner to pick up the prescriptions. Erika was referring to an example where she was not aware about the organizational processes informing the funding of medication:

I had to fight with the pharmacist because he told me I don't get the [name of drug]. I need an approval of the senior physician (...) There are so many errands involved: when I have a prescription from the hospital I have to go to the general practitioner so that he re-writes it. Then I have to wait there forever although he is really nice and everything. Then you have to go two, three, four times to the pharmacy because they have to order everything and cannot order two at once, they order one after the other. It is incredibly time-intense (Erika, 31-01-2011, L220-233)

Erika's quotation illustrates the work that she has to do to get her medication. Her work is ruled by the box-system that informs the Codex for Reimbursement of medication and implies that certain medication requires approval by a senior physician to ensure coverage by the respective sickness fund (see Chapter 1). Anna was also pointing to numerous extra ways and how challenging it is if you are alone and not as mobile – she is grateful that the father of her children has a car and does support her. Also her mother supports her and consults the senior physician or pharmacy on her behalf. As gaining the approval by the senior physician is mainly a textually-mediated process, meaning that the physician would primarily rely on the prescription and records from the attending physician at the outpatient clinic, Anna does not necessarily have to show up for each visit herself and somebody else can get this the work done for her. The women do plenty of work that goes beyond the local work setting of the outpatient clinic at routine visits and happens in trans-local work setting but is coordinated to arthritis-related health care. Such work includes also time and effort that women spent on reflecting and negotiating what they were told or recommended in arthritis-related health care.

6.3.1 Authoritative knowledge

The ruling relations privilege particular knowledge, namely knowledge that is shaped within a biomedical perspective and draws upon medical concepts. This knowledge can be referred to as an authoritative knowledge that organizes the construction of the patient as subordinated once she comes to seek health care (Smith, 1990b). The women's accounts in the hospital records are ideologically organized and address a conceptual and factual knowledge rather than the work knowledge of the women based on their experiences (Griffith, 1995). Professionals have the authority to translate experiences into factual accounts by using concepts within the institutional discourse. For instance, in the physician's SOAP notes, some notes related to 'Subjective' were not stated in lay terms but already transformed into a technical language. The authoritative knowledge of physicians is coordinated to the ruling relations and coordinates also women's consciousness into the ruling relations. For instance, Lisa elaborated on a conversation that she had with her physician due to her and her partner's desire for a child:

I have always been told (...) wait until it is as good so that you don't have to take any medication. Then I said Well, I have it already quite some time now and we will never ... and I am getting older. Then I asked once So how does it look like. At that point in time I was also taking [name of medication]. And the doctor said, really hard like bone – I think I was crying then again and again for a week – he said No. I can forget about my desire for a child. I have to accept that, that is not meant for me. (...) The rationale behind was that it is irresponsible to discontinue the medication. He was also flipping through my hospital records, and said that I have it already such a long time and it is also not to be expected that I will come into a symptom-free phase and that is irresponsible. He could not know that this would be a tragedy for me. I believe it would be a tragedy for many women. I left the room; I tried hard to not fall into tears when still in the consultation room. Once I opened the door, I started to cry immediately. I called my partner – with him, we talked right from the beginning that we would like to have kids (...) to some extent I saw the relationship in danger. Although I was always sure about that and he is not at all this way. (Lisa, 15-03-2011, L622-646)

Lisa described in this quotation all the work, including negotiating her fears, emotions, and concerns, that occupied her once she left the doctor's office. This work did not become visible or accounted for in the hospital records. What can be thought and talked about in the hospital records is already organized and common sense to those who are active in the work setting and activate the texts mediating the ruling relations (Walker,

1995). The institutional discourse based on biomedical concepts justified why the physician was not concerned about Lisa's desire for a child. He ensures that concepts are used consistently throughout all processes. Lisa's desire for a child extended beyond objectifiable accounts and shift attention to everyday life; he was ensuring that his work remains accountable to the institutional processes. The physician provided rational facts based on his medical knowledge, which is ruling arthritis-related health care. His knowledge is authoritative in this work setting and subsumes Lisa's experiences. Her feelings, fears, and emotions remained unattended; and so is her continuous work of informing herself about any possibility to become pregnant despite the disease, as well as consulting another doctor at the same clinic to gain an additional perspective. All these efforts and time, until she and her partner eventually decided for a pregnancy despite the disease, is left invisible.

Similarly, Veronika was describing an incident where the physician was referring to her hospital records in coming to a decision about her treatment plan. She consulted a physician at the outpatient clinic that she had never seen before. This statement of Veronika points implicitly to the changes in attending physicians' at the outpatient clinic. In the consultation to which Veronika is referring, she was told that she could not continue the medication, which she has taken before she became pregnant, as it would be too costly, and her symptoms have always remained the same rather than getting better when she was on the medication. The latter would be considered as a sign that the medication does not show an effect. The doctor recommended her another medication based on these grounds (Veronika, 05-05-2011; phone conversation). Veronika did not agree with him:

I insisted that I take [name of the drug] again. Because for me, despite everything, over three years I have had [name of the drug] and it is good for me. I was able to live and work. And that is all what I want. The pain that the young doctor was arguing about – he saw me the first time – that I have still pain at this location. You know, he said, it is measured all the time and that's how the activity of the pain is; always the same number. I am first of all left-handed, and of course I complain there, because I am using my left hand. I am not sitting around, but rather I am working and nursing. I don't have a moment of relaxation. (Veronika, 18-05-2011, L 39-48).

While Veronika draws upon her work knowledge, the physician based his arguments on a long-term evaluation of the VAS pain scale, which is from Veronika's point of view not representative for how she is able to be active in daily life. What can be thought about is coordinated to concepts and categories that inform the institutional discourse and has grown historically. Establishing this authoritative knowledge is not something that occurs in a moment in time, but rather has grown historically (Smith, 1990b). Veronika was talking about attitudes of previous generations toward the health care system:

That is still from the old school. What the doctor says is holy. You know. That is still this generation. White coat, it is the lovely god, so to speak. (Veronika, 18-05-2011, L329-332)

Veronika is pointing to the old school; Julia refers to the authority of physicians as normal within the Austrian system. She highlights how the authority of physicians is deeply entrenched in the system:

Well, of course, that is just how it is with us, that the doctors have much saying. I mean everything becomes more relative though when you have doctors amongst your friends. Yes, then you think, okay they are also only humans and don't know everything. But still. (...) if somebody would have told me earlier, or if a doctor would have told me 'Take care of your diet' ... that would have a completely different significance. (Julia, 21-03-2011, L53-58)

Katharina is also accepting the authoritative knowledge of physicians. As she was speaking about one of her current encounters with physicians, she described it at first as rather collaborative, for example, referring to 'we' – pointing to herself and the physician – when referring to treatment decisions. Toward the end, however, Katharina expresses her helplessness as a patient:

Now I do have the results of the computer tomography ... well the pictures, however, it is the case, that there is something insight now, but we have now to – that is also part of it – wait until it is swollen again, because then we can remove it, basically out of the ankle. At the time when it was swollen, we made therapy – Lymph drainage – so that it would go away. Now ... we have to wait again until it becomes swollen. Well, on one hand we can do something, but then we have to wait again. Basically there are times when you as patient are helpless. (Katharina, 20-07-2010, L224-233)

This feeling of helplessness is not something that would fit into the institutional discourse as it is an experience that can hardly be expressed in biomedical terms. Erika and Julia also referred to the helpless position of being a patient, in particular when you are in a stage of doing badly. In such situations they just wanted to get help from their doctors. They described that it is difficult to speak up for yourself and ask for information or claim your rights in such situations as you just want to have release of this situation of being in pain, being hardly able to move, and totally out of energy.

As informants have lived with the disease over time, they were referring to how they became more and more familiar with how things work in the system as well as gained more experience of living with the disease. Some informants referred to instances where they were listening to what the doctor has to say and respect their authoritative knowledge, but after all, decided for themselves what works best for them based on their work knowledge. For instance Marissa is very straight forward and says

“There have been weeks where I did not take any [medication]. (...) they cannot force me to take anything, and basically it is my decision. He [the physician] responded then that is not been really good, but yes, they have to accept this.” (Marissa, 19-08-2010, L351-366)

The quotation from Marissa illustrates how some informants respect what the physicians recommend to them, however, they also decide based on their work knowledge and what is coherent with their daily lives. Some of the informants were referring to how they think already ahead of time what information they would like to have and make notes so that they can ask for it at their next visit. The work that goes into thinking ahead, preparing notes, reflecting on one’s treatment, etc. is not appearing anywhere in the hospital records. Veronika was referring to a treatment plan that she was recommended to follow:

“The first week I had to take it three times: in the morning, at noon and the evening; then 5 mg in the morning, and the evening for another week, and the past week only once a day. In addition CaldeVit, but I became sick of it, I cannot take it anymore, I am getting sick. I stopped it. (...) but certainly, I tell the doctors that I became sick and discontinued it. And osteoporosis I have of course. (...) But now I should take it again every day – I cannot do that anymore. My stomach cannot do this anymore. Regardless what I eat or drink along with it.” (Veronika, 18-05-2011, L 499-510)

Veronika was feeling increased pain in her joints at the second meeting. She was referring to the ups and downs throughout the years, the course of the disease, and justified some changes and fluctuations in her health condition with various factors, including the weather. Also Julia noticed some changes in her health and was referring how she has been sick over a few weeks. She was describing how many people in her immediate environment are having stomach flu; moreover, she is consulting an alternative medicine-woman who suggested her some changes in diet. Julia put time, effort, and intent into figuring out what her recent symptoms could be; as the stomach flu resolved itself she concludes that all things might have been interrelated. This work of informants that comprises the continuous observation of their health status, making sense of differences that may occur at times and sorting out their bodily experiences based on their work knowledge, becomes easily obscured by the historically grown authoritative knowledge that rules arthritis-related health care. This authoritative knowledge has grown historically (Smith, 1990b) along with the allocation of public health care funding. The women were referring to work that they are doing that extends beyond of what is covered within arthritis-related health care.

6.3.2 Complementary treatment

As the arthritis-related clinic, which is the point of entry of this study, is a public clinic, in the hospital records, more specifically in the list of service codes, services are noted that are funded by the public health care system. The List of service codes mediates textually what becomes funded within the organizational processes in arthritis-related health care. Some of the informants were referring to treatments or additional applications that they engaged with related to the disease, disease-related symptoms, or not disease-specific, which are not covered by sickness funds. Based on the women's work knowledge and experience the acknowledgment of such treatments by physicians working within the Austria public health care system that is mainly based on traditional Western medicine is very limited.

It is not transparent what she [Julia is referring to a woman she is consulting for alternative treatment] is doing. But she evaluates all possible things, assesses the kidneys, the liver, and I cannot describe it at all what she is doing exactly. But she always meets the point how I am as a person and tries ... I am there not that long.

And at the moment I am doing rather, despite that I have significantly reduced my medication and hardly any take, I am doing extraordinary well. And that's why I said probably it is due to her. If it is due to her, I don't know. I am sticking to it for now at least. (...) Any traditional Western medicine man who hears what she is doing would jump up and say For God's sake, in such things you are investing money! But I think traditional Western medicine is not the only thing. (Julia, 24-02-2011, L413-431)

Later on Julia continues talking about the coverage of treatment costs by sickness funds and the lack of information for other forms of treatment that have to be privately paid.

Traditional Western medicine men never think about, that alternative treatment might help, or for them it is just impossible that alternative treatment could help. (...) Well, I cause a lot of money for the sickness fund with all the medication. But now when I reduce my medication and still find some help with some alternative things I cause less costs for the sickness fund but invest my own money. (...) That you have to search yourself and find what suits you. And I mean, not everyone can relate to that and believes in it. (Julia, 24-02-2011, L487-499)

The work that goes into finding out about treatment options that go beyond public health care, having the financial resources to engage in private health care or complementary/alternative treatments remains unnoticed in the hospital records. Julia, as well as Lisa, would not have been able to pay for all the treatments they considered in addition to the publicly available health care services; their respective families have provided them with financial support for alternative treatment. Julia and Lisa are debating on what it actually does for their health. Their reference to health is comprehensive and addresses their overall health, including their well-being, and not merely disease-related symptoms. Julia for instance felt that it is benefiting her and she also hopes that it enables her reduced medication intake.

Yes, because basically I think that all these things do somehow, I mean (...) because I believe that there are – how should I put it – also other possibilities available than just traditional Western Medicine to improve it and not to remove it. I am not assuming that I will get rid of it ever again, yes, but that I can take less medication; due to alternative things. And I do this energy work and go to this woman and notice that I am doing well and that there is something going on in my body that affects the entire thing. (Julia, 24-02-2011, L442-451)

The purpose for Julia in engaging in this form of therapy is to find a way to reduce her medication intake over time. Julia is hardly able to put in words what the woman who she

is consulting for alternative treatment actually does. What makes her trust this person is that she makes quite accurate statements regarding how Julia is as a person. Also Lisa is engaging in alternative treatment. For Lisa alternative treatment is something complementary that is worth trying out at times:

I don't have the feeling that I need something additional. Overall, I believe I have tried quite some things and did not make good experiences with all of them. I am trying things out from time to time, but not because I have the feeling it is not enough, but rather maybe there is still any other possibility. Especially now that I am doing a little bit worse and I don't want to take [name of medication] again right away. (Lisa, 09-05-2011, L443-469)

Lisa is pointing out that she has tried various things, indicating that she spends time and effort finding out about various alternatives. Her intent in actually engaging with these forms of treatments was to improve her overall health. Overall, without the support of her parents, Lisa would not have been able to pay for all these services. Further to the financial support, the women were describing various sources of gaining information about medical and complementary treatment.

6.3.3 The textual production of the informed patient

This section focuses on how women were provided with information in arthritis-related health care, as well as how they applied various means to gain further information about rheumatoid arthritis and its treatment. Medication intake was a significant part of the women's daily routines. As described in chapter 5, the first thing that Anna did in the morning was taking her medication. Lisa described that she was taking medication always in conjunction with her breakfast. Since her baby-son was born, her morning routine changed and subsequently also her times for medication intake. Also for Julia it became normal to take medication in the morning. This particular routine changed though as she and her partner started to plan for a second child:

Well, now I feel really weird because I am only taking cortisone every other day. The week when I am not taking the birth control pill, I don't have any medication to take every other day. And that is really weird: in the morning when I go to the shelf, I say to myself 'You are not taking anything'. That is so unfamiliar because I always throw in something in the morning. But that is really weird. (...) Yes, that is when I think it is the exact opposite for me. Where others think, weird you

have to take medication, it is not normal for me when I am not taking any medication. (Julia, 13-04-2011, L189-202)

The quotation illustrates that medication intake is an integral part of Julia's morning routine. Even when she is off medication she thinks about it and dedicates time and effort to the medication.

In reference to medical treatment, more specifically to disease-modifying antirheumatic drugs (DMARDs), the women received an information letter about the respective drug and had to sign a consent form. The prescription of DMARDs has been recommended based on scientific evidence as the 'mainstay' in people with rheumatoid arthritis (Smolen, Landewé, et al., 2010; further details are outlined in Chapter 2.1, The medical condition of rheumatoid arthritis). The information letter is handed over to informants and remains with them; the signed consent form is compiled in the hospital record. The information letter represents the written information about the drug that the women take away from her visit to the clinic. As a text, this letter coordinates the women's work regarding medication intake to the ruling relations. The overall structure of the information letter is depicted in Figure 9.

Patients have the right to be informed about all the issues addressed in the information sheet and once they were provided with the information by a doctor and have read the information, they have to give consent that they have understood and comprehended all the information about the drug and agree on the treatment. The information sheets and consent forms are issued by the Austrian Society for Rheumatology and Rehabilitation (ÖGR) as becomes apparent on the letter head of the consent forms (ÖGR, 2011). Once the woman signs the informed consent letter, her signature signifies her agreement on taking on responsibility of knowing about the drug, how to administer it accurately, and monitor for any expected effects as well as for side effects.

Letter head of Austrian Society for Rheumatology and Rehabilitation (ÖGR)
Information for Patient and Consent Form for [Name of drug]
Information about the drug Course of treatment Expected treatment effect Duration of treatment Implications if treatment does not show effect Possible side effects Possible side effects for which the patient has to watch for Indications for the necessity of urgent medical consultation Things to consider during treatment: -Required follow-up visits -Contra-Interactions with other medication -Vaccination -Contraception Implications if medication was forgotten
Consent form Date and Signature of patient Date and Signature of physician who provided the information

Figure 9: Structure of Information letter about drugs²²

Anna has integrated the information covered in the information letter about the expected treatment effects already in her way of speaking about medication:

²² Figure 9 was developed based on the content and structure of information letter for drugs (in German language) available for download at ÖGR (2011).

I had to discontinue the other medication. Now I have a new one. (...) If that has an effect, I don't know yet. I received the second one past Tuesday. Well, I have to wait for 6 months to see whether it works. (Anna, 14-02-2011, L 333-335)

All informants engaged in work that included thoughts and considerations about whether some symptoms or bodily experiences require seeking medical care. Marissa described how she sorts out various symptoms continuously and has kept a diary about her health already over years. She makes notes if she has stomach flu, a cold, or fever, or any other symptoms that cause her discomfort.

Furthermore, the women take on responsibility for performing blood tests regularly as outlined in the section about 'Things to consider during treatment'; doing this work allows doctors to monitor the treatment effects. In the information letter, it is also stated what individuals have to consider regarding contraception and taking the respective drugs. For most drugs, a detail description is provided in the information letter about how far in advance medication has to be discontinued prior to conception. Implications are outlined for how to proceed when medication intake is forgotten; this information, along with the information outlined in the section about the course of treatment in the information letter, indicates that individuals cannot just go off and on the drug or change it as they would like.

The details addressed in the information letter become institutionally accountable, and thus, also reportable and recordable in the hospital records. For instance, if the women do change medication intake on their own, a note would be made in the hospital records at her next visit to the outpatient clinic. Another example is the planning of pregnancy: once a woman declares her desire for a child, a time-plan is made and reported in the hospital records, when the woman has to discontinue the drugs, until when she has to ensure contraceptive security. For instance, the following entries have been made into informants' hospital records:

Veronika: "Desire for a child; once pregnancy is planned [drug] has to be discontinued; continuation with contraception for further 6 months" (08/2007)

Marissa: "No DMARD; patient would like to become pregnant" (04/2008)

This example illustrates how the information letter is a text that coordinates the work of informants in taking medication to the work of the physician, and subsequently to the ruling relations of arthritis-related health care. The knowledge base informing the information letter about contraception textually mediates that DMARDs do not have to be prescribed when conception is aimed for. Such information becomes reported in the hospital records and becomes institutionally accountable. Also, if a woman would go on and off the drugs at the discretion of her own, this would also become recorded in the hospital records as the entry in Marissa's record (see Section 6.2, The organization of the production of hospital records).

The information letter along with the women's signature on the informed consent letter coordinates her consciousness to the relations ruling arthritis-related health care. The work described in the previous paragraphs related to and coordinated by the information letter contributes to the production of the informed patient. Moreover, the information letter provides an ideological frame for the work of informants in their daily lives that is institutionally accountable. While the informed consent coordinates women's work to organizational processes within arthritis-related health care, women's work knowledge is further informed by various sources of information.

The situated nature of work related to the production of the informed patient

Information was something that came up in various contexts and in reference to various topics: for instance having too much information, not having the accurate information, lacking information, and being doubtful about the information. Lisa, Veronika, and Erika are health professionals by professional background. All three underscored that their professional knowledge and background is a resource in navigating the health care system. Lisa provides an example how she is not just taking for granted what doctors say given her experience of working in the system and noticing that doctors also make decisions that she does not always agree with as these decisions are not necessarily based on a thorough reflection of various available treatment options and interdisciplinary perspectives. Lisa's professional training allowed her not only to engage critically with her treatment, but also to reflect upon and integrate the disease as part of her life. Also

Erika's background and professional knowledge as a health professional allows her to speak and understand the medical concepts, and thus, to appropriate the institutional discourse of health care. Given her training she is aware of her rights as a patient:

For sure, if you know the vocabulary a little bit, if you can help yourself slightly – I mean I also don't know everything. You certainly have it easier in reading materials, or you have it easier in understanding what you are told, and you have more courage to ask why, how, and what is that or what other possibilities are available, and so on. That certainly helps me. And also, that you know you have certain rights as a patient – what many patients don't notice. I also had changed and now I tell myself I have the right, the possibility, that I get various information and want to know about it, and that I want to be informed exactly about it, and not just being told superficially about the field. But rather, I do want to have a definite answer and for so long until I really understand it. That is simply my right. That helps for sure. Certainly. I think one has to move away from listening to the authority. That cannot be it. That you take and swallow everything you are told without even challenging what one is actually talking about. Certainly, the training helped. (Erika, 09-03-2011, L93-106)

Like Erika, also Veronika has a health professional background too. When caring for her mother-in-law, she ensures that she can do the nursing work in an ergonomic way as she is mindful of her own health as well. Due to her health professional background, she has information about what assistive devices and aids are available to make her work more ergonomic. Another meeting with Veronika took place right before she had to undergo several screenings, including X-rays of the lung, to check her eligibility of a particular medication. She brought already previous X-rays with her so that the doctor could review the results in light of possible changes; she recalled that she experienced pneumonia twice and doubted whether any signs would become visible in the X-rays that would have an impact on her eligibility for certain drugs. The way Veronika was talking demonstrated that she is able to appropriate the institutional discourse and understands the rationale of the physician based on her professional background and clinical experience as health professional.

Anna does not have a medical background; she also mentioned several times that she has hardly any friends. She trusts the health professionals and consults them in case she needs information or advice. The following example illustrates how Anna engages in additional orthopedic treatment that she has to pay privately. She wants to ensure that she is not

doing anything that would interfere with her treatment at the clinic; she consults her orthopedic doctor to gain clarity or ask for advice:

Yes, I am always there [at the public clinic for orthopedics at the hospital]. I also had surgery there and I told the doctor about it [that she is consulting a privately funded orthopedic doctor outside the hospital]. He said that is okay, that I am going there. Because I don't want to do anything wrong because that doesn't pay off for my hip. (Anna, 14-02-2011, L128-135)

Not only the knowledge due to some informants' professional background made a difference; also the personal relations provided informants' with varying information and thus resources. Marissa's boss recommended her specialists and information about a special diet. Erika was describing how a friend supported her in getting an appointment at a special clinic.

In reference to treatments outside the public health care system, some informants relied also on the information of family members: for instance Julia's father provided her the contact of a woman who provides alternative treatments. He consulted her himself and was very satisfied and thus, found it would be good for Julia too. Also her sister gave her a book on diet especially for rheumatic diseases. All informants, except Veronika, mentioned that they search for information on the internet. How they make use of the information varied though. For instance, Katharina was referring to instances where she found information that confirmed her work knowledge. Lisa had times, in particular throughout her pregnancy, when she prohibited herself searching the internet as she was becoming upset with all the different things that could happen to her child. The examples outlined in this section illustrate how the information letter serves as a text to mediate the work of informants related to medication intake to the ruling relations of arthritis-related health care and allows for the production of the informed patient. Part of the work that goes into producing the informed patient is signing the consent form; the women's signature also implies that she takes on responsibility in following the information that she has received. In addition, women deploy various resources depending on their social context and situatedness to gain, understand, and comprehend further information.

6.4 Discussion

The textual analysis presented in this chapter along with the ethnographic accounts of the women delineated how the diversity of the women's work knowledge becomes organized within the same generalizing ruling relations. The particularities, as well as the unique resources and needs drop away in the arthritis-related health care; only what can be captured within the concepts ruling the relations in arthritis-related health care is accounted for. In the remaining section of this chapter I discuss how the ruling relations do not account for the complexity of the women's daily life and the various resources that are available to the women. The various resources lead also to diverse work knowledge of the women. The daily life of the mothers with rheumatoid arthritis is not happening in a standardized way, but rather unfolds continuously as the women go about their lives.

The complexity of daily life remains unattended in arthritis-related health care as textually mediated by the hospital records. The HAQ-DI contains for instance questions about getting in or getting out of bed and the biometrician records morning stiffness, however, as the ethnographic accounts of the women illustrated, these matters cannot be seen in isolation from other demands and needs in daily life. For instance, Anna does not have severe problems in getting out of the bed, however, it is challenging for her to support her children and get them ready for school once she got out of bed. Veronika did not refer to the morning stiffness that caused her a problem, but rather the vibration of the mowing lawn-mower had a lasting impact on her throughout the night and interfered with her mothering activities.

In the socio-demographic questionnaire, which the women completed at the very first visit to the outpatient clinic, they indicated their family and employment status and type of paid work next to other socio-demographic characteristics. If their situation changed, such as they get married, get a child, or change employment, this information may remain unnoticed or it may show up in the continuous documentation. Activities of women such as informal care giving or preparing food for the family would not show up in the hospital records. The consequences and implications, the requirements of the respective work, are not taken in any consideration within the ruling relations of arthritis-related health care in the work setting of this outpatient clinic as Veronika pointed out (see

quotation Page 15). The work of the women in the locality of the clinical setting contains work such as waiting and completing forms; once they leave the clinic, much work is going on beyond this setting. For women daily life becomes accomplished within their social context and in accordance to their resources and their needs which may change over time. The work that women do such as taking medication, attending routine visits and regular blood testing, or monitoring the disease is the same for all informants, however, their experiences and resources are diverse, and thus, also their work knowledge varies. For the women, however, living daily life with rheumatoid arthritis is a lived reality – something that they have to negotiate and integrate continuously into their daily lives.

The analysis of the hospital records disclosed that the understanding of health is informed by a medical concept. Hospital records can be seen as texts that are “embedded in and integral to forms of organization where immediate contact with that aspect of the world to be processed is not the responsibility of those who make decisions” (Turner, 1995, p. 236). The physician was most often referred to by informants in terms of health professionals. This may underscore the strong medical emphasis in arthritis-related health care, as well as the dominant and powerful position of the medical profession in Austria (see Chapter 1). Wendell (2008) has referred to the power of medicine to transfer personal experiences into rational facts as cognitive authority. Cognitive authority refers to medicine’s priorities of controlling the body are placed over the individual experiences and needs (Wendell, 1996). Cognitive authority is enacted when “the specialist offers the correct understanding of reality while the lay person struggles in the relativity of mere opinion” (Addelson, 2003, p. 170). Medicine is supposed to hold the knowledge about the body, has the power to transfer the inner experience of the body into observable causes or rational facts without any reflection on the experiences and actualities of the other person (Wendell, 2008). The cognitive authority of medicine and what counts as legitimate knowledge within health care arrangements remains often unexamined. Institutional ethnographers elaborate on how actualities become transferred into facts:

“The actual events are not facts. It is the use of proper procedure for categorizing events which transforms them into facts. A fact is something that is already categorized, already worked up to conform to the model of what that fact should

be like. (...) If something is to be constructed as a fact, then it must be shown that proper procedures have been used to establish it as objectively known” (Smith, 1990b, p. 27).

The medical doctors transfer actual events, such as the women’s experiences, into categories that fit into medical conceptualizations. When the woman consults with the doctor, the doctor would follow the SOAP-notes; the application of this structure to make notes is part of the proper procedure toward establishing facts. The ethnographical account of the women in this research illustrated the work that goes into negotiating, challenging, questioning, and accepting this authoritative knowledge. The authority of medical knowledge is deeply entrenched in the health care system and historically grown that it becomes a taken-for-granted, appears as natural and remains for the vast part unquestioned as some of the women’s accounts illustrated. Ruling relations are set up in a way that employment and family as a lived reality become overruled in arthritis-related health care. Nevertheless, medical doctors apply their authoritative knowledge also in regard to questions such as whether a woman with rheumatoid arthritis wants to become pregnant. While the medical doctor approaches pregnancy from a medical perspective, for the woman it is a lived reality, an actual event that cannot be simply reduced to medical concepts.

As women are informed by the medical doctors about their medication, and asked to give their written consent, they agree on taking the medication timely and regularly and watching for intended and unintended effects of the drugs. The thoughts and actual practices when it comes to taking the medication every morning or not taking it anymore, are not showing up anywhere in the hospital records. The treatment-plans regarding medication are clearly stated and presented in a straightforward manner for each informant in the hospital records. The standardized documentation and structure within the hospital records allows for an abstracted version of individuals’ experiences that can be entered into measurable and objectifiable knowledge. This documentation serves the relevancies and purposes of health professionals whose job it is to manage the medical condition of the patients; however, the circumstances and experiences of daily live are obscured (Walker, 1995). The work of health professionals is coordinated with medical research: for instance it is recommended in the literature to conduct regular follow-up

visits between rheumatologist and patients with active disease activity every three months (Smolen et al., 2010), as well as annual radiographs of hand and feet (Villeneuve & Emery, 2009). Based on the women's work knowledge, they have integrated this routine as well. The ethnographic accounts presented in this chapter illustrated the work that is required from the women to make this routine happen. The work of the women varies depending on their social situatedness and the resources that available within their social context.

Within the scope of a medical perspective, illness is described as an objective label (Weitz, 2007). An identified medical problem leads logically to medical treatment. Such a perspective on illness informs also the Austrian health care in which the individual is constructed as 'patient' who is in need of care and subsequently a passive recipient of health care (SV, 2010). This logic results in the marginalization of treatments that fall outside this logic such as alternative or complementary treatment (Barry & Yuill, 2008). Alternative or complementary treatment remains unregulated in the Austrian health care system (Gibis, Koch-Wulkan, & Bultman, 2004), which implies that such treatments are not covered within the public health care system and individuals have to pay for such treatments themselves. As the informants of this study were describing, alternative or complementary treatment is not only unregulated, and thus not financially supported, but lacks also ideal support from some professionals active within arthritis-related health care.

Patients with rheumatoid arthritis have reported in previous research that they lack information about the disease, and about content of and accessibility to treatment and health care (Kjeken et al., 2006; Meesters et al., 2011). This research disclosed the comprehensive work that women do regarding information about disease, content and access to treatment. Their accounts disclosed the various ways of gaining and seeking information, as well as making sense of information. The women did not only draw upon the information letter which they were provided with in relation to a particular treatment; they were also seeking for information in the internet, received information and discussed information with family, friends, and their boss and colleagues, and relied also on their

own work knowledge as a valuable source. The sources of information varied though depending on the situatedness of the women in the social relations.

Informants are not only coordinated to the organizational processes of arthritis-related health care, they also have to negotiate, for instance, their social and health insurance status and ensure that they can sustain a livelihood. Social and health insurance status is tied to employment in Austria as illustrated in chapter 1. Thus, employment and employment-related matters were also referred to by women as part of their work that they do in their everyday life. While the focus in this chapter was specifically on organizational processes related to arthritis-related health care, the focus of the next chapter is on organizational processes relevant to employment.

Chapter 7

7 Negotiating textually-mediated realities related to employment

Sorting out employment and reconciling it with the complexity of women's daily lives is crucial within the Austrian system not only for earning a livelihood, but also to maintain social insurance status and hence ensure one's social rights (see Chapter 1). Employability, invalidity/ capability to work, and disability are three textually-mediated realities that emanated significantly from interviews and participant observations and are thus further explored in this chapter. For example, Katharina invited me to accompany her to the labor market office (AMS) as she had an appointment there; and Anna illustrated her work of filing various documents related to her social benefits and in particular her invalidity status. Furthermore, over the course of the study, each woman was referring at some point to the disability pass that they could apply for. Except for Anna who had already a disability pass, all informants intentionally put time and effort into avoiding being seen as disabled. These realities opened up in the daily lives of the women.

In the analytical description provided in this chapter, I drew upon the women's work knowledge, that is, the women's knowledge that they have of how they do go about what they do in their daily lives (Smith, 2005), and to map out how their doings are coordinated with those of others. This chapter integrates ethnographic accounts of Katharina and Anna and textual analysis to explicate the relations that rule the organizational processes of receiving unemployment benefits and assistance, of maintaining invalidity pension once it has been granted; as well as accounts about the work of all informants of resisting 'disability'. The focus of the analytical description in this chapter is on mapping out the intertextual hierarchy shaping the work at the labor market office. As such, I depict in this chapter how higher-order, or regulatory texts, enter into the organization of the work in this setting (Smith, 2006). In the third section I refer back to the historical development of disability policies in Austria to further

understand the work knowledge and experience of women. This chapter concludes with a discussion on the interrelatedness of these three realities.

7.1 Maintaining 'employability'

In this section I provide an ethnographic account of Katharina's appointment at the labor market office to change her status from being on sick-leave to unemployment, and of Anna's descriptions of her previous encounters with the labor market office. This and the subsequent section of this chapter refer in particular to accounts about Katharina and Anna as they have been the only two informants whose work, in the institutional ethnographic sense, was coordinated to the labor market office or pension insurance institute.

Katharina had an appointment at the labor market office to which I accompanied her. Throughout Katharina's meeting a Consultation agreement was set up. This agreement constitutes an active text in this work setting and is taken up in the analytical description to explicate the relations ruling the practices of receiving this particular kind of monetary social benefits. Katharina was unemployed at the time of her participation in this study and received social assistance (Table 3). More specifically, Katharina was on sick-leave when she initially enrolled in this research and her status changed to being unemployed over the course of the study. This change of status is coordinated to and by the labor market office.

The generalizing character of the ruling relations became further transparent in Anna's descriptions of her work toward receiving invalidity pension. In one of our meetings, she described though the processes that she went through until she was eventually granted invalidity pension. Anna was already granted invalidity pension at the time of her study participation. The organizational processes that are in place regarding eligibility for invalidity pension require that an individual has received unemployment benefits as well as social assistance for a certain period of time prior applying for invalidity pension. Table 6 provides an overview of the eligibility criteria for unemployment benefits and social assistance (second column) along with Anna's way of describing her experience of going through this organizational process (third column).

Different kinds of benefits	Eligibility for benefits (AMS, 2011b; BMASK, 2010b)	Anna's description (01-02-2011, L51-62)
Unemployment benefits	<ul style="list-style-type: none"> - Entitlement for benefits based on record of unemployment insurance period - Availability for vocational mediation - Employability - Willing to work and take on a reasonable job 	<p>I received unemployment benefits.</p> <p>Then I wanted to continue work, but I did not manage that.</p>
Social assistance	<ul style="list-style-type: none"> - Record of previously received unemployment benefits - Needs-base - Granted until a person receives pension benefits 	<p>Since then I am at home. I received also social assistance for some years.</p> <p>And then I submitted the things because I could not do it anymore.</p>

Table 6: Eligibility criteria for unemployment benefits and social assistance

As this Table illustrates, to be eligible for unemployment benefits and subsequently social assistance, it is important that one is unemployed, employable, and willing to work. Katharina had an appointment at the labor market office as she recovered from an ankle-surgery and the period of her sick-leave ended. Katharina's visit that day was intended to report her end of sick-leave. When granted social assistance, payment continues for the first four days of sick-leave; then the recipient of social assistance has the right of receiving sickness-benefits (AMS, 2011b).

The coordinated work of accomplishing a Consultation agreement

If an individual is registered with the labor market office, meaning that she is unemployed and seeking employment, the labor market office has to be informed about the end of sick-leave immediately to ensure continuation of social benefits (AMS, 2011b). The end of the sick-leave has to be recorded by a medical doctor. By the time Katharina arrived at the labor market office, she was informed that the woman she is normally consulting with is out of office, but another service agent would meet with her. The visit contained setting-up a Consultation agreement and completing an application

form for social assistance. The meeting of Katharina with the service agent started with the following conversation (quotation is taken from my field notes):

Service agent:	So you are healthy?
Katharina:	Well, as far as you can say that one can be healthy when having a chronic condition.
Service agent:	Okay, I see. So, are you able to work?

Noteworthy in this conversation is the change from “being healthy” – a concept that did not capture adequately Katharina’s experiences from her perspective – to “being able to work”. This part of the conversation signified that the service agent coordinated the consciousness of both – himself and Katharina – into the ruling relations of the labor market office which are primarily concerned about Katharina’s employability. The service agent continued asking Katharina questions and entered notes into the computer. Then he printed out a document, entitled Consultation agreement, and asked Katharina to review and sign it. He did the work that he was supposed to do in this work setting; this work was already organized and established in a certain way so that it became easily manageable for him.

The socially organized and coordinated work of the service agent and Katharina illustrates how the Consultation agreement becomes accomplished as an official letter. The agreement follows an official and standardized structure, including a letter head, explicit statement of contact details, and a signature of a representative of the labor market office. The language used in the contract is addressing the individual who receives the text and is written up in the second-person account. For instance, in Katharina’s account, it is stated

“you are looking for a new workplace; you have health-related limitations that have to be considered in the search for a new work place; you are expected to look for jobs yourself by using the self-services at the AMS, and respond to calls or e-mails from companies who want to get in contact with you” (personal translation out of Katharina’s Consultation agreement).

Toward the end of the agreement, it is stated that this contract is valid until its expiry which is stated on top of the agreement; other than that the General Business Conditions are valid. Figure 10 illustrates how the Consultation agreement occurs as a course of action within this work setting. The white boxes at the lower right side illustrate the parts of the Consultation agreement; the light-grey box behind the white boxes describes briefly the components of the Consultation agreement. These components indicate its standardized character; the middle-grey boxes in the upper left corner track the relation to the legal framework that informs, regulates and authorizes the Consultation agreement.

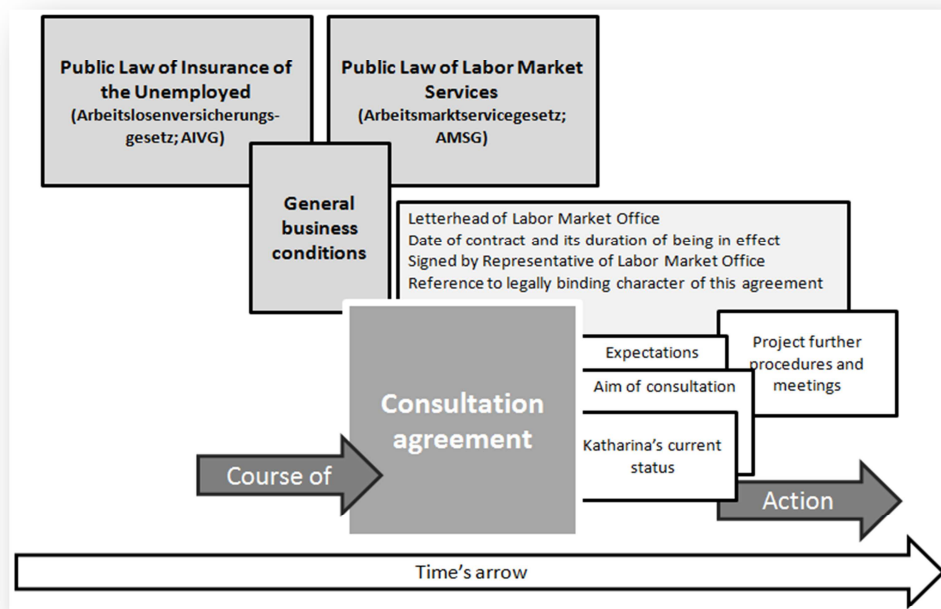


Figure 10: The organization and coordinated work of a Consultation agreement at the labor market office²³

This Figure depicts also how the Consultation agreement is embedded within an intertextual hierarchy. The Consultation agreement refers to the General business conditions; the General business conditions refer then further to the Public Law of

²³ Figure 10 was developed within the scope of this dissertation.

Insurance of the Unemployed, as well as the Public Law of Labor Market Services. These laws do not only provide the legal framework for the Consultation agreement; they also serve as the regulatory texts. Regulatory texts are not active or visible in the actual setting, but coordinate other texts that become active in actual settings at various sites (Smith, 2005). According to the General Business Conditions, a Consultation agreement is made between the individual consulting the labor market office and the labor market office. The General Business Conditions foresee that all details described in the Consultation agreement are obligatory; if a violation of the agreement is happening, the labor market office is entitled to stop the payment of benefits. For instance, discontinuing a re-training program for which one has been registered without notification of the labor market office would be considered as a violation (AMS, 2011a). In the following sections, examples are provided of how the legal texts, and in particular the Public Law of Insurance of the Unemployed, serve as regulatory texts as they define the concepts used in this work setting and legitimize various actions performed within the labor market office.

Employability

Employability is defined in the Public law of Insurance for the Unemployed; employability is given if an individual is not invalid or incapable to work (§8 AIVG). If the service agent would be unsure of Katharina's ability to work according to §8 of the Public Law of Insurance of the Unemployed, he/ she can initiate an appointment so that her work-ability would be examined. In the case of Katharina, she was referred to the "Gesundheitsstraße" (this word is a composition of the word 'health' – Gesundheit – and 'street/ road/ route' – Straße). As the man at the labor market office explains to Katharina, the "Gesundheitsstraße" is a pilot-project in cooperation of the labor market office with the pension insurance institute to coordinate the process of applying for early retirement benefits due to disability more efficiently. The report that results out of Katharina's visit to the "Gesundheitsstraße", which would contain an evaluation of Katharina's employability, is subsequently obligatory for the labor market office and the old-age insurance institute. This means, if inability to participate in paid employment is assessed, application of early retirement benefits is automatically initiated, but if ability-

to-work is the result, then the labor market office takes further steps toward searching for jobs (BMASK, 2009b). The assessment at the “Gesundheitsstraße” contains an evaluation about demands that a person would be capable of doing, recommendations for medical and vocational rehabilitation, and estimations about a person’s employability (personal translation; BMASK, 2009b). No reference is given to who are the professionals involved in this estimation. Given Katharina’s experiences with previous assessments, she assumed that it would be a physician who has never seen her before and is employed by the insurance institute. According to §8 of the Public Law of Insurance of the Unemployed, the unemployed is obligated to carry out such a medical examination when requested upon by the labor market office. The medical examination would take place at a certified center, at another place, at another point in time. Such practices open up the organization and coordination of the work to multiple local settings and at various points in time (Smith 2006).

Thus, the reference to the ability to work is coordinated to the General Business Conditions of the labor market office and the reference of the latter to the Public law of insurance of the unemployed. As becomes obvious, the Consultation agreement mediates the legal framework into the actual practices of people and thus, serves as the textual mediator of the ruling relations. As soon as the service agent refers to the ability to work, the consciousness of both – the service agent and Katharina – becomes coordinated to the ruling relations. The legal framework provides the ideological frame for all the processes and procedures happening at the labor market office.

As depicted in Figure 10, the Consultation agreement coordinates what is going on within this particular visit at this work setting; it is a text that occurs as a moment of sequence in a course of action and links Katharina’s status quo, which also contains information of her formal professional training and her previous work experience, with further procedures in the future. The middle-grey box behind the Consultation agreement outlines some features of the contract that make it an official document and legitimize the work of the service agent at labor market office. The Consultation agreement mediates Katharina into the consciousness of the institutional discourse of the labor market office: she was told in the consultation agreement what she would be able to do, what she would

have to do, and she was informed about the legal framework that legitimizes all the statements. In the Consultation agreement it was stated that Katharina was informed verbally about the legal consequences for her in case she is not following the agreement. However, this information was not provided to her in the actual meeting. Thus, the course of action rests on the assumption that Katharina is already aware of this information and the seriousness of this agreement based on previous encounters with the labor market office. While Katharina appears to be personally addressed, she is not addressed as an active subject or agent in this setting. Rather, the concepts of unemployment, employability, and willingness to work are assigned with agency and serve as a function of the institutional discourse. Katharina's status quo was described within the boundaries of the concepts of unemployment status, employability, and willingness to work which justify her eligibility for social assistance. The Consultation agreement becomes "the effective reality of the institution in terms of what can be taken up or treated as real in subsequent workings of the organization" (Eastwood, 2006, p. 186). The contract does not only identify the concepts that become institutionally accountable but also defines the boundaries of the concepts, and thus, what becomes recognizable within the institution (Eastwood, 2006). The legal texts, as regulatory text, organize the processes, concepts and expression within subordinate texts, including the General Business Condition and the Consultation agreement. While the regulatory texts are not visible when the Consultation agreement becomes accomplished in the actual setting, they "operate to produce out of particular actions done by particular people in a particular time and place an organizational/institutional process" (Smith 2006, p. 83).

The concepts contained in the consultation agreement are coordinated to the legal texts that serve as regulatory texts. Once Katharina signed the contract, she indicated her consent on all terms and conditions, and consequently, also took on responsibility for the 'successful management' of her employability.

The generalizing character of the ruling relations

The Consultation agreement, as active text in the work setting, coordinates the consciousness of people to the regulatory texts and has a generalizing character within

the ruling relations. This text is activated in an actual observable setting by actual people. Its standardized character within the ruling relations allows that anybody who is familiar with the organizational processes can set up the contract with any client. While the consultant, who Katharina is normally with, is out of office that day she has an appointment at the labor market office, another service agent steps in and sets up the contract with her. The regulatory texts are not necessarily prescribing any actions, but rather establish

“concepts and categories in terms of which what is done can be recognized as an instance or expression of textually authorized procedure. (...) It is the recognizability of what is done or being done as an instance or expression of the regulatory text (rather than rationality) that accomplishes an institutional process or procedure” (Smith 2006, p. 83).

Despite that Anna consulted the labor market office at a different point in time and at a different district office in another province, she is ruled also in these relations and has to follow the same processes and procedures. Anna is describing how she has registered with the labor market office as she wanted to work and find a new job, but she could not work up to what she was expected by the labor market office:

I have been at the labor market office. They asked me why I registered with them. I said ... I wanted to. I do want to go to work. And then they offered me a few things, that I should do easier tasks. Or how do you call it – also re-training. And I have been there. I did not make it. Because the entire day in front of the computer – either my eyes became swollen or the entire spine hurt, or the hands were stiff. (...) I did that for one, two weeks or a month or so, I don't know it exactly anymore. If I could not make it one day, I would call in that I would not be able to come. Oh, well you have to organize yourself and that's how it works there. You have to be there! [Anna is imitating the response] I changed a few things in my life, but it did not work out. (Anna, 01-02-2011, L268-278)

At first glance, Anna meets the demands inherent in the concepts of unemployment, employability, and willingness to work. Nevertheless, as Anna's example illustrates, willingness to work is not necessarily satisfied by “yes, I want to go to work”. The concept of employability implies that the individual is fully available at any time to the schedules and conditions prescribed by the labor market office. Anna participated in re-training programs, which was agreed upon in her Consultation agreement. Anna was not able to make it to or through all re-training sessions given the fluctuating nature of her

disease. However, she was told that she has to organize herself to make it work out. The demand put on her by the labor market office is part of the ruling relations and refers back to the General Business Conditions of the labor market office (AMS, 2011a). The fact that Anna is not able to attend the re-training sessions is likely seen as a risk of her violating the Consultation agreement. As outlined earlier, such a violation would legitimize the labor market office to discontinue payment of unemployment benefits (AMS, 2011a). Anna tried to meet the expectations of the labor market office and attend all appointments. However, she was not always able to do so given her disease as she described in the quotation stated above. Anna was granted invalidity pension at some point, as outlined in Table 6, and thus has to manage her ‘invalidity status’.

7.2 Managing ‘invalidity status’

Invalidity or incapacity to work pension is also part of the social benefits granted by the Austrian welfare state. As shown in the previous section, services and benefits related to unemployment insurance (including unemployment benefits and social assistance) are coordinated by the labor market office. Applications for invalidity pension or any other business with pension insurance are processed directly with the pension insurance institutes. Anna received fixed invalidity pension in 2010 for two years at a time. Hence, at the point of her participation in this research she was on invalidity pension. In this section I elaborate on the work that Anna has to do to maintain her invalidity status and how this work is coordinated to the textually-mediated ruling relations of the pension insurance. Being granted invalidity pension was a release for her:

I always receive a letter in January, stating that I receive what they have granted to me. Back then I was told that I receive pension until 2012. I don’t know now what happens then. I am really glad that they helped me, because I was occupied with the labor market office. They called me in every time as if they would not believe me. What shall I do, I don’t know. I tried a few things, like such courses, that I would be re-trained. It did not work. Today, I can go, you see, now it works. But what happens in two years from now, I cannot predict. (Anna, 14-02-2011, L660-666)

Anna highlighted in this quotation her experience of being ruled in the organizational processes: she expressed a lack of understanding of the nature of her disease, while the people active at the labor market office followed the organizational processes that have

been established based on the regulatory frames of this work setting as described in the previous section.

The organization of maintaining “invalidity status”

In the first sentence of the quotation stated above, Anna referred to a letter that she had received in January 2010. This letter was a notification about the continuation of her invalidity pension until 2012 and constituted a moment in a sequence of continuing organizational processes as shown in Figure 11. The letter that Anna received is illustrated by the box in the middle and coordinates various organizational processes, including Anna’s work. The letter contained a formal structure and provides references to its legal frame, namely the General Law of Social Insurance and the General Law of Pension. Any document attached to this letter contained a File Reference on top of the page which included various letters and numbers including Anna’s social insurance number (files attached are illustrated by light-grey boxes on the right top of the Figure 11). The purpose statement referred back to the letter that Anna has received in the previous year (light-grey box at left bottom of Figure 11), and directed into the future by stating that she will continue receiving invalidity benefits (light-grey boxes at right bottom of Figure 11). The letter is a moment in sequence of various work processes and embedded within a course of action that has started previously and is continuing in the future.

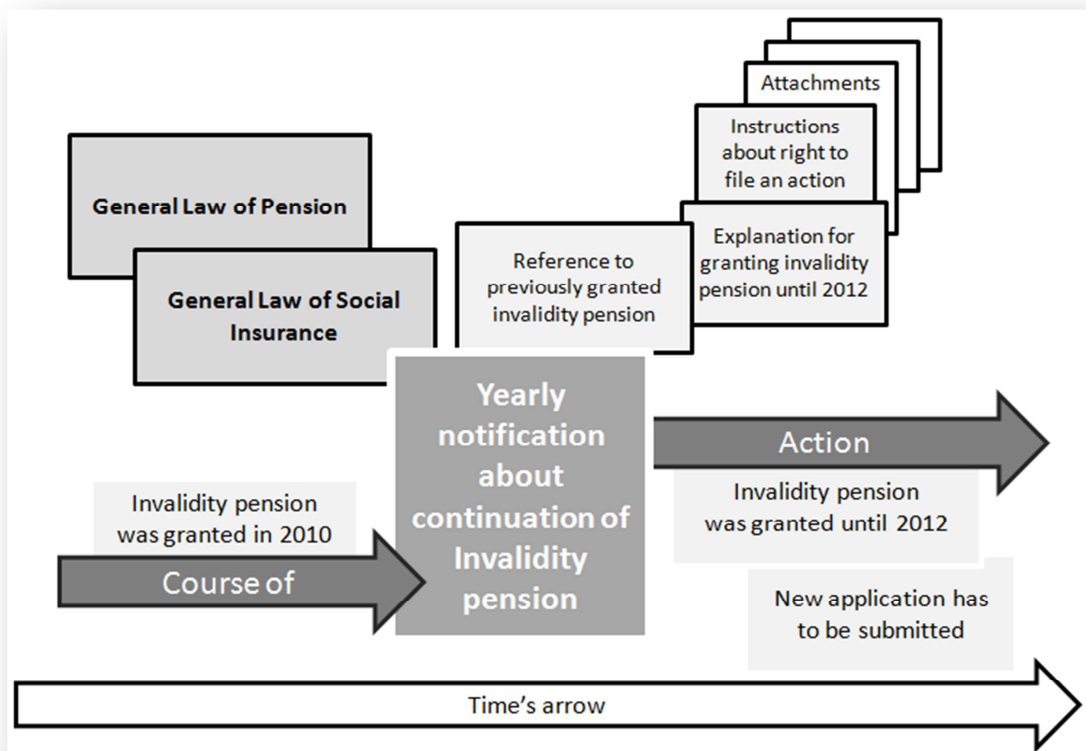


Figure 11: The textually-mediated organization of maintaining 'invalidity status'²⁴

The legally binding character of this text is supported by the instructions about Anna's rights to file an action. As the Consultation agreement with the labor market office, also this letter is embedded within an intertextual hierarchy: reference is given for instance to the letter in which Anna was actually granted invalidity pension; to the legal framework of this letter; and to a medical examination. The legal framework serves also here as the regulatory text. The work of putting all these fragments into one letter allows for recognizing this text as "an instance of the procedure within the intertextual hierarchy" (Smith 2006, p. 87). The fixed period of invalidity pension was justified by an earlier medical examination.

²⁴ Figure 11 was developed within the scope of this dissertation.

The textual reality of feeling “invalid”

In the notification it was explained that if Anna would still feel invalid by the time her invalidity benefits would expire, she would have to submit an application the latest within three months after the expiry date. Anna referred already to future actions in our conversations, namely once invalidity pension expires, she has to submit a new application:

I have two years now, until 2012. Then I will receive an invitation that I come again. The nicest thing is that I receive a letter from them, as it was the last year, and they say as far as I can recall Miss A. are you still feeling ‘invalid’? Did you get better or are you still feeling that way? Why am I getting such a letter? Chronic polyarthritis (...) I have the disease, it won’t go away ever. Back then I had only the knees, now I have everything – the shoulders, neck, hands, what shall I say? (Anna, 14-02-2011, L631-640)

As this quotation illustrates, Anna has to negotiate the concept of ‘invalidity’ that she is assigned with: this concept is the foundation on which her application for continuation of invalidity benefits would be based on, but which does not make sense to her given her experience and work knowledge of living with rheumatoid arthritis. The term invalidity, as it is used for blue collar worker (or incapacity to work in the case of white collar worker; see Chapter 1) refers only to the extent an individual is able to pursue paid employment. Invalidity is determined based on a medical examination by a certified doctor of the pension insurance institute. In case of invalidity, the individual is subsequently entitled to receive invalidity benefits.

Invalidity is a rather negatively laden term pointing to the defects that an individual experiences. The term goes back to the law for the compensation of invalids in 1919, and is still in use (Naue, 2006, 2009). The notification that Anna received is thus part of the organizational processes that are textually mediated and do not refer to or account for Anna’s actualities.

Anna’s work within the organizational processes related to pension insurance entails reading the texts carefully and following the instructions accurately: this may include showing up at scheduled appointments, adhering to suggested timelines, including the expiry date, and filing all the texts. Possible concerns of Anna about how she could

manage employment if invalidity pension would not be extended after two years were addressed at no point. The organizational processes follow a textually-mediated reality that leaves the actualities of the women's daily life unattended. The concepts ruling the relations are assigned with agency and define and set the boundaries for what becomes accounted for within these relations.

7.3 Resisting 'disability'

In this section I drew upon the knowledge and experience of the informants gained through interviews and participant observations, as well as on literature about disability policies in Austria. I took this body of literature into account to explore how the historical development of disability policies and related discourses infiltrate into the daily lives of mothers with rheumatoid arthritis. The usefulness of reviewing the historical development of disability policies evolved based on the dialogue with the women. While disability may become a textually-mediated reality as soon as an individual would apply for a disability pass or claims disability status, the reference in this section is on the work that women do to resist being assigned this label and manage the discourse surrounding disability.

All informants pointed to 'disability' at some point in time. Except Anna, nobody had the disability pass; however, all referred to work that they are doing to resist the label of disability. When talking with the women about their work knowledge and experience, there was no apparent text that would mediate or coordinate their consciousness into particular ruling relations regarding disability. Rather, Austria has signed the Convention of the United Nations (UN) on the rights of people with disabilities in 2007 and ratified it in 2008. The convention ensures that people with disabilities are granted full and equal human rights which implies that all laws and regulations are revised and set up accordingly (BMAASK, 2009a). Most of the informants highlighted that their work knowledge is shaped by what they were told by their parents. This reference directed me toward literature about the development of the discourse on disability over time. Thus, in this section I engaged primarily with the historical development of disability policies and how this development shaped the view about disability in Austria which the women mainly referred to and which most informants tried to resist in their daily lives.

Marissa has informed herself and decided that this pass is not anything for her:

No, I resist that. Well, that is something I want in no case; that I know for sure. I had thought about it once, but that was before she [her daughter] was born. And I have thought, basically, I don't want that because there are not only advantages with that. But rather you are labeled and then you certainly have disadvantages with that. That's why I said no. I likely would have gotten it. (Marissa, 19-08-2010, L265-271)

Like Marissa, Lisa also does not want to engage with any relations related to disability. She works hard so that nobody would think she has restrictions:

And I don't want that anyone, that there exists the possibility, that somebody says, well of course, again this. I don't want that anyone is thinking, I am less able or productive than anybody else. I don't even want that such a situation would come. If the situation would come once, I think that would be tough for me. (...) They [referring to health professionals] also told my parents about the disability pass in the past; they also told them that they should try applying for release of prescription fees. But this is recorded and then it could happen at some point that somebody is referring to that and says Oh, no, you had a release of prescription fees, oh, there is something, we are not going to take you. She [referring to her mother] always said she doesn't want that. It might be a barrier on my future way. She doesn't want that. And I do have the same attitude as well. Well, I also don't want that. Because then I have at some point – this may sound weird now – but then I have the label – I don't need and want that. (Lisa, 15-03-2011, L1118-1136)

In Lisa's talks she is bringing into view how her knowledge about disability regulations is coordinated to the implicit learning from her parents. She took over the attitude from her parents that being "labeled" as a person with disability may create challenges in the future, in particular when it comes to paid employment. Lisa points in this quotation also to the release of prescription fees and how it might show up in some other records. The Federation of Social Insurance Institutes forwards actually once a year the information about individuals who have a release of prescription fees to the labor market office. People who have a release of prescription fee are also not charged with the service fee for the electronic health card. This service fee is normally paid by the individual's employer (AMS, 2011b); however, individuals who are registered with the labor market office as they are unemployed, are not charged with a service fee for the electronic health card.

Lisa and Marissa were talking about their resistance in quite a natural sense by referring back to what they were told by their parents. Lisa is very explicit that nobody ever told her that she is less able or productive; however, she learned that people might think that way once you have the “label”. Similar to Lisa’s parents, also Erika is talking about preventing her children, who have been diagnosed with juvenile rheumatoid arthritis recently, from the “disability-label”. These examples illustrated how the mothers invested time and effort in talking and reflecting with their parents about disability and thinking ahead about future implications.

Keeping the disease invisible

Informants put time and effort into maintaining their disease invisible so that nobody would interpret the disease as disability. Veronika and Erika are cautious about not disclosing the disease as it may cause disadvantages in the future:

Except for my family, my friends (...) I told nobody because Oh my goodness, Sick-leave. I was the most two times on sick-leave and then it was really severe because recovery took longer. Two weeks, but only two times. But still, if I would tell anybody about it – uuh, you need extra-treatment, you need injections, is this infectious? You know how people are; if somebody doesn’t know it, then ... (...) I know that probably the time comes when my status becomes worse and then it changes anyhow (...) being not able to work anymore. There is just no reason at this point. You don’t get a position. You don’t get work, not even as cleaning lady. (...) Despite all you cannot see that I am ill. I am full of energy and have a big mouth. (Veronika, 18-05-2011, L390-408)

You have to be incredibly cautious whom you tell what and how much. Because people just don’t know how to deal with it, they don’t have the sensitivity that you should not talk around these things. You are neither doing yourself something good nor your children if people know about it. Unfortunately it is that way. (Erika, 31-01-2011, L737-741)

As these quotations illustrate, the time, effort, and intent that some of the informants spend to keep the disease invisible contains keeping track of one’s sick-leave, or being cautious whom to tell about the disease. Furthermore, Lisa and Marissa underscored that they would make up for any challenge by putting extra-effort into something so that nobody would even have a chance to think that they are less able or productive.

The historical development of the perspective on disability in the Austrian society

The work that informants described here related to resisting 'disability' and keeping the disease invisible illustrates how they put a lot of effort into 'living a normal life' so that they are not assigned the label of having a disability. Numerous definitions of disability are in place in Austrian policy-texts and laws depending on the subject area. However, what all have in common is the medical focus that defines a person with disability based on functional limitations which lead to a deviation from the expected norm (Naue, 2009). The historical development of policies related to disability start in 1919 with the law for compensation of invalids, and a law from 1957 that regulated the care of persons with war injuries (Kriegsopferversorgungsgesetz). The law from 1957 is still in use and entails a decree (Richtsatzsverordnung), which outlines principles for the determination of the degree of disability and lists "states of suffering or illness" and "health defects" that lead to reduced productivity (Naue, 2006). From the early beginnings, disability was thus assigned to people who were outside the norm and caused increased costs to society given their unproductivity.

Given this perspective on people with disability, there was hardly any interaction between various stakeholders, such as representatives from different ministries, politicians from various parties, and people with disability. Rather, people with disability were presented with many difficulties and obstacles in becoming politically active. The disability movement has only started more recently and barriers – actual, material, and social barriers – still contribute that people with disability are a rather marginalized group in Austrian society. The public view about people with disability in Austria is far from envisioning people with disabilities as fully included in Austrian society (Naue, 2009). The historical development provides some insights as to how social and political participation is not necessarily a lived reality for people with disabilities at this point in Austria. The reference back to the decree within the law for the care of persons with war injuries, presents disability as an individualized, medical problem that does not necessarily call for any actions by society, including politicians, officials, and other people in positions to make decisions to facilitate social inclusion and participation of people with disability (Naue, 2009). Hence, the work that informants do in resisting

disability can be seen as work to resist becoming members of a marginalized group. While the textual reality as presented in laws and conventions is increasingly changing and showing a commitment to remove social barriers that people with disability may face in society, the lived reality and public view are still reflecting the historical development of the disability policies.

7.4 Discussion

The work that goes into managing employability, invalidity, and disability, as presented in this chapter, is related and in some way coordinated to the BMASK and were therefore presented together in this chapter. These two service agencies are both coordinated to the BMASK and share a common interest in ensuring that all citizens can participate at the labor market. However, the labor market office became a service agency under public law in 1994 and is as such administratively separated from the BMASK; the main objective of the labor market office is the minimization of unemployment. In contrast, the BASB is still administered within the BASB, and aims for the vocational integration of people with disabilities

Normative assumptions about employment and its implications on disability

Social benefits administered through the labor market office, in particular unemployment/ social assistance and invalidity are dependent on and coordinated to the employment status or employment history of the individual. While disability is not dependent on employment status, disability status is still evaluated based on a comparison with an individual who is of similar age and educational level. Thus, the norm that informs the relations related to the social services addressed in this chapter rely on the norm that people of employable age should participate in paid employment. If individuals are not able to do so, they are deviant from the norm (Clarke, 2010; Weitz, 2007). This deviance would then become afflicted with a moral status, which entails a judgment about the worthiness of the individual (Weitz, 2007). The work that the informants were describing was work to resist being exposed to this judgment. Most of the women in this study referred to the experiences and knowledge passed on from their parents. In the case of disability policies, it is not the informants who have actually read the texts; no active text

became apparent throughout interviews or participant observations. The parents of informants may have done so years back. Since then the disability concept may have been revised; however, the parents' read of the text entered succeeding phases of relation. Such relations include what the parents of informants passed on to them. The women were drawing upon the knowledge and information that they received from their parents. Smith (1990b) stressed that "textual analyses must explain how the text as petrified meaning structures the reader's interpretation and hence how its meaning may be entered into succeeding phases of the relation" (p. 223). The historical development of the disability policies became part of the analysis in this study to better understand the social relations that informed the informants' knowledge about disability. Such practice is in line with institutional ethnography as "[u]ncovering texts as constituents of relations anchors research in the actual ways in which relations are organized and how they operate" (Smith, 1990b, p. 224). Such relations are historically grown.

The experiences and work knowledge described by the women in this study are not accounted for in the social processes ruling the practices at the labor market office or the BASB. For instance, the informants' work of resisting being labeled "disabled" remains invisible. Part of this work is keeping the disease invisible. As discussed in previous literature, disclosing the disease may open up access to workplace adaptations and understanding about the disease from co-workers, however, it may also lead to resentments from co-workers (Gignac, 2007; Lacaille et al., 2007; Nilsson et al., 2007; Van der Meer et al., 2011).

Situated in diverse social relations

The accounts of the informants illustrated the work that goes into managing employment, invalidity, and disability as an Austrian woman and mother with rheumatoid arthritis. The work of the seven women is very diverse depending on their social relations and situatedness. Their situatedness informs their work knowledge and experiences: Marissa, Lisa, Julia, Erika, and Veronika were not ruled by these institutional relations. Anna and Katharina's institutional relations related to the labor market office were very significant in maintaining social and financial security. Anna expressed relief when she was granted

the invalidity pension as she was not able to keep up with the expectations of the labor market office. As Anna was talking she expressed that the nature of her disease was misunderstood by the labor market office, however, as the analytical description showed, she was ruled by an institutional discourse about employability. Challenges such as pain, fatigue, or problems with the joints, as well as the fluctuating and chronic nature of the disease, which Anna referred to, are not captured within this discourse. Reference is given frequently to health at the labor market office, for instance in ordinary language people refer to “being documented as healthy” when changing status from sick-leave to employable – also Katharina was asked by the service agent whether she is healthy; and the pilot-project Katharina was referred to is also named “Gesundheitsstraße” (see page 148). Nevertheless, the concept ruling the relations in this work setting is employability.

Further relations opening up through employment

Employment was not only mentioned in relation to social services and benefits, but also in regard to resources that extend beyond wages or benefits. Marissa highlighted how her boss provides her with literature about special diets; Lisa described that when she did her training in the health sciences which was located at the same university as the Rheumatology outpatient clinic she could call in when it would be best to come in for a follow-up visit and did not have to line up for an appointment. In the literature about social determinants of health it was described that higher social positions gained through education and one’s subsequent employment allows for access to social networks that can be relevant and helpful over the course of one’s life in terms of getting access to services as well as gaining and making use of specific information (Marmot, 2006).

Furthermore, literature about critical social transitions outlined that semi-skilled or unskilled individuals are more likely to become excluded from the labor market after onset of chronic illness (Blane, 2006). Such social disadvantages may have cross-sectional and longitudinal implications for the individual (Blane, 2006). In arthritis-related literature it has been described that the physical demand of work becomes less, and the possibilities as well as the flexibility at the labor market increases with increased education (e.g. Kaptein et al., 2009; Reisine et al., 2001)

Based on this research no such conclusions can and should be made about the impact of the educational or professional background on the employment history or on other life areas. What can be said from an institutional ethnographical perspective is that the informants' work, that is, the time, effort, and intent, which they had to do in their daily lives was informed and facilitated by varying resources given their social situatedness. Anna, who was on invalidity pension, expressed some dissatisfaction with the apartment in which she is currently living, and described that after getting a laundry-machine for herself, she can do laundry now in the apartment; however, this interferes with other activities as the apartment is rather small. She highlighted the challenges in using public transport and the hardship of getting groceries done by herself. Lisa was provided with various gadgets and devices by her mother and other family members that supported her with various housework, she and her partner were planning a new house and ensured that it is accessible, she got a new car, which suits her needs better, and when doing groceries she can leave heavier things in the car and her partner would carry it up to the apartment once he returns from work. These are just a few examples that illustrate how the work of Anna and Lisa is facilitated and shaped by varying resources that inform and influence the work in various areas of daily life.

Chapter 8

8 The everyday life of Austrian women with rheumatoid arthritis – Some concluding remarks

This research was concerned with how Austrian women, who are mothers, are of employable age, and have a diagnosis of rheumatoid arthritis, go about their daily lives as they are situated within the Austrian context. The starting point of this research was the disjuncture that I experienced in my clinical work with women who have been diagnosed with rheumatoid arthritis: the standardized assessments that I was supposed to complete with the women did not account for the complexities and actualities of their daily lives. Starting from this disjuncture, I was interested in learning from seven Austrian women with rheumatoid arthritis about how they actually go about their daily lives. I have argued at the beginning of this dissertation that it is crucial to disclose the actualities of their doings, and how their social contexts, including organizational processes, shape what they can do and do, to comprehensively understand the actual determinants of the women's life conditions.

Gaining the work knowledge of the women and understanding what they actually do has not been the totality of this investigation, but rather the starting point “to investigate the antecedents of people's activities and experiences within the institutional complex” (Sinding, 2010, p. 1657). The institutional complex has been, as outlined in Chapter 4, how women with rheumatoid arthritis, who are of employable age, and mother of at least one child, manage daily life which may extend far beyond what becomes assessed and accounted for in arthritis-related health care. I moved from a thick description of the actualities of their daily lives (Chapter 5) to a more differentiated view of how the women's daily life is socially coordinated to relations that rule arthritis-related health care (Chapter 6), as well as relations ruling social services related to unemployment and invalidity (Chapter 7). This research has shown how the women's actual work varies depending on their social relations. Nevertheless, once the women enter arthritis-related health care, or attend appointments at the labor market office, their different experiences become ruled within generalizing relations. The diversity, differences, and particularities

in the women's work knowledge and experiences are not necessarily accounted for in the ruling relations.

I started with the disjuncture in clinical practice; this research opened up the complexity of daily life and in particular the social organization of the daily lives of the seven women. The standpoint of the women who participated in this research, their experiences of going about everyday life, provided the point of entry into the territory that I aimed to discover with this dissertation. The women's experiences were not the analytical end (McCoy, 2005), but provided insights about how their daily life is socially organized, and opened up further understanding about the interface between the individual and the social context. Thus, in this chapter I draw upon various examples that emerged in this research that go beyond the disjuncture from which I initially started to explore the social relations shaping the daily lives of these women. Hence, the aim of this final chapter is not solely to revisit the disjuncture and discuss the findings of this research in a concluding manner; rather, I aim to reflect upon the insights gained from this research, integrate further accounts of the women, and express some implications emerging from this research.

This chapter is structured as follows: First, I address the taken-for-granted in the daily lives of the women who participated in this study, and reflect specifically upon the emphasis on family and employment within the Austrian context. In the second part, I return to the varying ruling relations disclosed in this research. I argue for dialogue rather than monologism to facilitate a more efficient and coherent system that acknowledges diverse perspectives. I also underscore in this section the value of attending to the experiences of individuals, albeit using an approach that avoids individualism, and illustrate my arguments with the example of disability in Austria. I conclude this dissertation with some reflections on institutional ethnography and its implications for occupational science.

8.1 The taken-for-granted in the daily lives of Austrian women

As outlined in the literature review in this dissertation, the dominant mode of knowledge generation about the daily lives of women with rheumatoid arthritis is characterized by a focus on the individual with a medical condition. Women with rheumatoid arthritis are frequently described in terms of their functional limitations that may impede their occupations. Understanding how daily life becomes accomplished directs attention to the social organization of daily life. This study has illustrated that these women engage in various activities; the time, effort, and intent that is required to get the work done varies though. The ethnographic accounts disclosed in this research illustrate how certain activities, such as the woman as main caregiver for the children who takes on most of the housework, become normal and taken-for-granted. DeVault (1991) conducted an institutional ethnography about the work of feeding a family and highlighted that the “workful” character of this activity is often unrecognized even by those who do it” (DeVault, 1991, p. 228). Tracing how these doings are situated within the social context and coordinated to social relations puts the taken-for-granted under scrutiny. Mapping out the social relations and disclosing normative and taken-for-granted assumptions allows for making the ‘workful’ character of these doings explicit.

In Austria, social policies have been set up to strengthen the role of women in Austrian society as main caregiver and housekeeper (Leitner, 2003; Sauer, 2007; details are outlined in Chapter 1.3). The change to part-time employment was described as a rather typical form of employment for Austrian mothers with young children (Bergman et al., 2010; Knittler, 2010; Notz, 2010). The explicit familialism expressed through social policies in Austria (Leitner, 2003), and the accounts of the women in this research illustrate how social structures and related practices and processes become accepted “as a normal way of life for themselves and fellow community members” (Galvaan, 2012, p. 155). Choices that the women made about what they do are rooted in what they consider as normal for themselves, what is congruent with their communities (Galvaan, 2012), and what becomes possible within their context (Laliberte Rudman, 2010).

The women who participated in this research have very different resources available in their everyday life, and are coordinated to varying institutions. For instance, some work of Anna who is a single mother and lives on invalidity pension is coordinated to the pension insurance institute; Katharina who lives on social assistance is coordinated to the social organization of the labor market office; Lisa, Marissa, and Veronika were on maternity leave throughout their participation in this study – part of their work is coordinated to family benefits; Marissa is additionally engaged in paid work and thus also coordinated to the company she is working for. Depending on the social relations and situatedness of the women, different possibilities and resources for what they can do and did in their daily lives opened up. In some few instances, such as in the case of the mandatory leave, women are actually left with no choice and social structures determine what they have to do. Nevertheless, none of the informants challenged for instance the mandatory protected paternity leave eight weeks before and after giving birth (BMWfJ, 2011b).

Much of the work that the women described and carried out throughout the course of this research remains invisible, and yet, ensures that the emphases on family and employment within the Austrian system become accomplished. Julia, Lisa, and Marissa referred to it: they lived with their respective partners for some time; all three mentioned that they were planning to get married. When asking them why they want to get married, they mentioned that this is just part of being a family. Julia highlighted that her partner does not necessarily see a reason for getting married, however, for her it is a significant symbol of belonging together and being a family. These examples illustrate how the traditional family model becomes accomplished in everyday life. For instance being married, providing informal care, providing and relying on informal care, become doings that became taken-for-granted, even if not always without challenges, for the seven women who participated in this study. The informants' accounts in this research delineated how specific features of familialism, such as the traditional family or informal caregiving within the immediate family become accomplished in everyday life.

Occupational scientists have argued that paid work is highly valued in Western society due to the historical influence of Christianity along with the industrial revolution.

Individuals who are not able to participate in paid work, such as women who are informal caregivers, homemakers, or people with disabilities may be perceived as being dependent on society (Kantartzis & Molineux, 2012). When norms rest on ideals of able-bodied individuals whose contribution to society is valued based on their paid work, then work that goes into caring for the family, negotiating the disease, attending appointments at arthritis-related health care, being cared for, or resisting disability remains unaccounted for.

8.2 Daily life of Austrian women with rheumatoid arthritis ruled in different relations

The findings of this research exemplify how arthritis-related health care is ruled by relations that rely on an understanding of health based on medical concepts. As distinguished from arthritis-related health care, the relations ruling and coordinating the activities at the labor market office, as well as the pension insurance institute when it comes to invalidity pension, refer mainly to employability. Once the women enter into ruling relations such as in arthritis-related health care, or at the labor market service, accounts of the diversity of their experiences and resources drop away. In contrast, within informants' daily life, the disease, and employment are strongly interwoven though. For Veronika it would make most sense to coordinate social and health care services as she illustrates in the following quotation by drawing on a very specific, and yet for her very relevant topic:

Let's take the entire story about my injections. The person [pointing to a physician] who decides does not know me at all or what I do. I have rheumatoid arthritis, I am this age. But what I do is not stated anywhere. Because for me it does make a difference if I work in the office and live with this disease, or if I am a nurse, work in the health care system, and do physical work. (...) I know that it [pointing to medication that she used to take before her pregnancy] is expensive but it helps. And despite its costs, it is still cheaper as if I would not have it, the social insurance institute would tell me you are not capable of doing anything, you cannot go to work – you have to go for invalidity pension. Then I accumulate much more costs at the expense of the state. That's why I don't understand the system. Why do they cut back on these things? There is a reason why I take the medication, why I received it up front, and why I need it long-term. (...) If I would be on invalidity pension and account for all the additional benefits that the state would provide me, like housing benefits and so on – it would be three times

as much in comparison to one times the costs of the therapy. (Veronika, 18-05-2011, L329-367)

Veronika points in this quotation to a disjuncture between what she does in her daily life and how she engages in physical work despite her disease, what is considered in arthritis-related health care along with treatment decisions, is not necessarily coordinated with social services and benefits. Veronika's quotation summarizes and illustrates the medically dominated ruling relations in the Austrian health care system, the strong emphasis on employability in ruling relations at the labor market office, as well as the pension insurance institute. I suggest based on the findings of this research to re-evaluate what is needed to make the prevailing ruling relations a more efficient and coherent system that considers a multiplicity of views rather than ruling relations distinct from each other with no accountability for dialogue and efficiency.

Though it is not foregrounded in the organizational processes and ruling relations, the ruling relations based on medical concepts and employability rely on the norm of the able-bodied individual. Any deviance from this norm is described in the ruling relations within arthritis-related health care in terms of medical concepts, and in regard to the labor market office, or pension insurance institute in terms of employability. As outlined in Chapter 6, the medical profession holds cognitive authority in arthritis-related health care. In matters related to the labor market office, or pension insurance institute, the medical profession serves also as a social control agent. While the medical profession is a powerful player in the health care and social system, the relations ruling the respective system, along with its organizational and administrative processes and practices, are distinct.

Some may argue that the medical dominance in health care does not constitute an issue as the main objective of health care is the treatment of sickness (Busfield, 2000). Looking upon arthritis-related health care from this perspective, one can argue that care provision is effective in its own right and ensures that individuals with rheumatoid arthritis have regular follow-up visits with the rheumatologist as outlined in internationally agreed-upon treatment-recommendations (Smolen, Aletaha, et al., 2010). Moreover, the ruling relations in arthritis-related health care are set up so that the individual patient receives

information and consents herself to take on responsibility (see 6.3.3, The production of the 'informed' patient). It could be argued even further that the unmet need in health care, namely employment of people with rheumatoid arthritis, described in previous research (Lacaille et al., 2007; Van der Meer et al., 2011) is justified and does not constitute a problem as employment is not a domain of health care. In turn, it could be argued that while employment is outside the domain of health care, there are service providers and institutions that are specifically concerned with ensuring participation of individuals in paid employment, such as the labor market office and the Federal Office for Social Affairs and Disability (BASB). The primary focus of the labor market office is to minimize unemployment in Austria; and the main objective of the BASB is full integration of people with disability at the labor market. Mapping out the social relations in this research illustrated the administratively distinct, and yet, in daily life complementary and interconnected relations of arthritis-related health care and issues regarding employment and related social services and benefits.

Cross-sectoral planning and service provision between health care and the labor market office or pension insurance institutes is complex as these services are supervised by different ministries. If cross-sectoral planning and service provision does not exist, it does not mean though that it is not needed; rather, the lack of cross-sectoral planning and service provision implies that the actual work that goes into communicating and collaborating across sectors may rest with the individual women as illustrated in this research. Their work in negotiating and managing across sectors remains invisible though. Their work contains actual work of consulting various professionals, and providing certificates at various offices, but also understanding, comprehending and navigating the different ruling relations. Occupational scientists Whiteford and Pereira (2012) have argued that to ensure full participation of people in society, services have to be effective in themselves, as well as to the overall community. The services provided in arthritis-related health care, and by the labor market office, may be effective in their own right. Nevertheless, to ensure full participation in society for women with rheumatoid arthritis cross-sectoral collaborations are critical.

8.2.1 Engaging in dialogue about what can be known and is known

Given the findings from this study, in particular the further understanding of the ruling relations and the work that the women do to go about their daily lives, I argue that a discussion about the basic principles and assumptions informing the distinct ruling relations is needed. In this regard I consider it worthwhile to revisit Bakhtin's reference to monologism versus dialogism that has been referred to in institutional ethnography (Smith, 1999; 2005). According to Bakhtin, monologism refers to a condition where values, perspectives, and practices become subordinated into a single perspective (Bakhtin & Holquist, 1981; Gardiner, 2000; Smith, 1999). For instance in arthritis-related health care, a monolog prevails around a medical conceptualization of health. The values, perspectives, and practices that the informants have described, that inform their actualities of living with the disease become subordinated into the medical perspective. Similarly, in practices at the labor market office, the chronic, fluctuating nature of the disease becomes subordinated to the perspective of employability. Rankin and Campbell (2006) pointed out that "[h]ow we know determines what we can see. More importantly, it determines what we can see to be a problem" (p. 182). What goes beyond concepts ruling the relations does not become attended to in the organizational processes and practices at the respective services.

Thus, I argue that it is important to unsettle established concepts that rule the distinct relations, and to critically reflect upon monologisms that have historically grown within social structures, and that rule organizational processes till today. I envision such discussions to go beyond monologisms and allow dialogue to happen to facilitate cross-sectoral planning and service provision. Furthermore, diverse perspectives have to be included to ensure that the values, perspectives and practices that have been previously subordinated to particular perspectives are accounted for as well.

8.2.2 Attending to the experiences of individuals

I draw in the remainder of this section on the example of the informants' reference to disability to illustrate the value of attending to and integrating the experiences of individuals in aiming toward relations that are comprehensive and conclusive. The informants of this research are situated within the social context of Austria that reflects a historical development of disability policies based on a deficit-oriented perspective about people with disability. Disability is evaluated based on the productivity of an individual in comparison with a person of same age and profession. This perspective on disability has meant contributing to the development of a context in which being assigned with a disability can be rather marginalizing in society. This development, along with the women's accounts in this study, illustrates how disability is situated in the social context and accomplished in daily life. While policies have changed more recently, the public perspective is still strongly informed by the historically entrenched deficit-oriented perspective (Naue, 2006; 2009). On the policy-level, disability is considered as a cross-sectoral matter; the integration of people with disabilities in political concepts and actions across sectors is called for (BMASK, 2010a). This development led to the generation and integration of various definitions of disability into federal and provincial laws in line with the aims and objectives of various sectors (BMASK, 2009a). For instance, the General Social Insurance Act (ASVG) draws upon a definition of disability that facilitates the allocation of social benefits; and the Austrian Federal Act on the Equalization of Persons with Disabilities refers to a definition of disability that is concerned about participation in employment (BMASK, 2009a). Thus, on the policy-level, disability becomes conceptualized to inform organizational processes and practices in the respective service provision. In contrast, the reference to disability by the informants is based on their experiences and work knowledge. As disclosed in this research, this perspective was passed on from one generation to another. Most of the women who participated in this research engaged in work to resist being assigned with the label 'disabled', since being disabled might be associated with being less productive in the public view.

Thus, this research suggests that despite the changes on a policy level, historical perspectives are still prevailing and impede change in the actualities of daily life. When

the Austrian Federal Act on the Equalization of Persons with Disabilities (BGStG) was drafted, the voices of people with disabilities were turned down by the constitution committee. Once the Act was released, people with disabilities were anxious that the Act may not bring any significant changes to their daily lives (Naue, 2006). Based on this research I cannot argue that the Act brought about significant changes or not. But I learned from the women that most of them spent time and effort to intentionally resist being labeled disabled. This work of the women was not accounted for on a conceptual level. I posit that any standpoint taken to disclose the very concrete, and yet complex work of individuals about how disability becomes accomplished is valuable and has to be attended when aiming toward understanding and changing such complex social relations. Smith (1997; 1999) has argued that no standpoint is privileged, but rather the standpoint taken discloses how concepts and theory become engrained in the actual practices of individuals whose standpoint has been taken. In the case of disability policies, the standpoint of lawyers, politicians, or ministers is as important as the standpoint of people with disabilities. Nevertheless, I second the institutional ethnographers Rankin and Campbell (2006) who have argued “there is much to learn from *what is actually happening* in the activities of the people ‘on the ground’ (...) what people know experientially needs to be legitimated instead of repudiated” (p. 171).

8.3 Implications for occupational science

Knowledge generation in institutional ethnography starts in the everyday life, with the actual experiences of individuals going about their daily lives, and traces then the social relations in which these experiences are embedded. Thus, as a social scientific approach, institutional ethnography supports occupational scientists in knowledge generation about the situated nature of what individuals do in their daily lives and how their doings are coordinated to and shaped by the social context. Mykhalovskiy and McCoy (2002) have argued that institutional ethnography is

“an approach to language that takes up people’s accounts of their activities as windows onto extended sequences of activity that are only partially visible in the accounts themselves (G. Smith, 1998). In reading for social organization, we tried to see how people’s activities were connected with those of others” (p. 29).

Starting with the activities of the informants in this research pinpointed to relations in daily life that shape and impact their everyday life. If Anna does not follow the time-lines of the pension insurance institute, her invalidity pension would expire and she would remain without income. Or if the women do not get the work done of getting an approval by the senior physician for a medication that requires such an approval, they would bear the consequences as would their children for whom they may not be able to care. Thus, as the women are situated with their bodies in actual time and place, their work is coordinated to, as well as organized and shaped by social relations.

The social organization of the daily life of Austrian women with rheumatoid arthritis illustrated in this research emphasizes the situated nature of what the women can do and actually do. Galvaan (2012), who investigated how individuals come to decide what they do, underscored that decisions upon and between occupations are made based upon the tacit knowledge and habitus of individuals; they are drawing upon what is congruent with their own values and beliefs as well as those of their communities. Smith (1997) pointed out that such tacit knowledge is basically the knowing about how we do things; for instance, the very ordinary things such as how to get laundry done, where to get groceries, or how to get medication. Such tacit knowledge transforms into knowledge once it enters language and is talked about. The experiences and knowledge that informants shared throughout interviews and participant observations is their tacit knowledge, the knowledge that underpins what and how they do in daily life. Institutional ethnographers start their inquiry with these concrete, tacitly known experiences of going about everyday life, and then turn then the gaze from the individual to the social relations in which the knowledge and experiences are situated (McCoy, 2005).

In starting with the all-encompassing notion of work, institutional ethnography allows accounting for the invisible work in daily life and unsettles the taken-for-granted of everyday life. Institutional ethnography is promising as it allows us to not only see the time, effort, and intent, that individuals spend in doing something, but also opens up how the doings are shaped by the social context in which the doings take place. As a method of inquiry it requires from the researcher to carefully attend to how individuals “can speak about their experiences as they do” (Mykhalovskiy & McCoy, 2002, p. 31).

Integrating the standpoint of individuals “calls for the researcher to avoid switching perspectives and recasting participants’ comments in conceptual terms” (McCoy, 2005, p. 804) and provides very concrete information about the actualities of everyday life. Taking the standpoint as a methodological stipulation (Turner, 2003), and starting from the experience of the individuals, provides an understanding of how everyday life becomes accomplished through the actual activities of actual people (de Montigny, 2007; Smith, 1987). In institutional ethnography experience is seen as dialogical; shaped and known socially (Griffith, 1998). Listening to the experiences of the women, mapping out and disclosing the work that they do in their daily lives, and situating it within the social relations disentangles the taken-for-granted and opens it up for discussions.

Now that I have the insights from this research, I understand the ruling relations of arthritis-related health care more clearly; the work that goes into producing a hospital record is ruled within and coordinated to particular relations based on medical concepts. At the same time, I also see more clearly now how the social context of Austria shapes and informs the everyday life of the women who participated in this research, and are mothers, and of employable age. I am honestly puzzled by the power of ruling relations that ensure that family and employment are hardly addressed in arthritis-related health care as illustrated in this study, despite their strong emphasis within the social context. Based on this research, I am amazed by how complex and yet coordinated and deeply entrenched the ruling relations informed by a medical understanding of health are within the Austrian health care system. Given the complexity of the social relations, I hope that I reach with this research people from various backgrounds, including the medical, health, and social sciences, practitioners, researchers, educators, and patients alike, to raise awareness about the social organization of our daily lives, about the relations ruling our lives, and about the coordinated activities of many individuals across places and time that ensure that these relations become accomplished.

The problematic (Smith, 1987; 2005), or territory that was discovered in this research from the standpoint of the women with rheumatoid arthritis, delineates how everyday life becomes accomplished through the socially coordinated activities of many individuals who are active at various places and at various times. Knowing the ‘how’ does not

constitute an end in itself. Rather, it provides me with more confidence to speak about the need to attend to the situated nature of what individuals do in their daily lives to adequately and comprehensively understand the complexity of daily life, and to ensure that the social organization of our lives becomes acknowledged and put under scrutiny. Whether taken-for-granted, accounted for, or visible, it is actual time, effort and intent that goes into accomplishing the very mundane and ordinary of everyday life ... and the work varies depending on the situatedness within the social relations.

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Appendices

Appendix 1: Interview guide for initial interview

[this is the translation of the German interview guide]

The woman is informed about the study and the study process. Once the woman provided consent on her voluntary participation in this study, the interview started.

I would like to ask you a few questions about your current living conditions. I would be interested in where you live, your marital status, the number and age of children living with you, type of education, work experience, current work status, current benefit status, etc. Please tell me whatever you feel comfortable with sharing.

Pick a day of the week that you feel is a fairly typical day given the things you do and describe this day? What happens, how does your day start, what do you do, who is involved in your typical day, how does the day unfold? What do you do during the day, what do others do? How is this day different than other days of the week?

Some probing questions:

- Ask informant to describe smaller units of her doings: for instance if informant would say that she has to get her child ready for daycare before she goes to work as she has to bring her to daycare on her way, I would probe her “You have mentioned that you have to bring your child to daycare on your way to work. Can you describe in more detail what you are doing from the time you get out of the bed in the morning until you arrive at your workplace?”
- Ask informant to focus on the actual description of how doings are coordinated: for instance if informant refers to completing forms required for certain services, I would probe her “You have mentioned that to get through all this paper-work you are consulting with the administrative staff. Can you describe what the term “administrative staff” comprises? What are they doing? In what ways do they interact with you?”

At the end of the interview:

I would like to follow up with you within the next couple of weeks and would like to join you for a few hours throughout your ordinary day. Would that be okay for you?
When and where would you feel comfortable in me joining you?

Appendix 2: Interview guide for final interview

[this is the translation of the German interview guide]

These are the texts which I have identified as relevant and influential in what you did. I tried to see where and how they interact with your doings and would like to discuss my understanding of these interactions with you.

We will review the texts together and I will explain to the woman how I see the texts relating to what she did. I will encourage the woman to elaborate on my understanding, to disagree, or agree, to clarify, etc.

The following thoughts will guide the discussion:

I recall that you got the text [from this person/service provider, at this office, etc.] and you returned it to [this person, this office, etc.] – Is this accurate?

What do you do after reading this text – would you say it has an impact on your occupations? If so, in what sense? For instance, does it provide you with information that requires you to do things differently? Does it require you to get in touch with other people, service providers, etc.? Do you have to follow-up with the person/the office/the service provider from whom you received the text? Does anyone contact you based on the responses you gave?

I also identified some texts that did not explicitly come to the forefront in the interviews or participant observations, but from my point of view these texts were implicitly influencing your occupations.

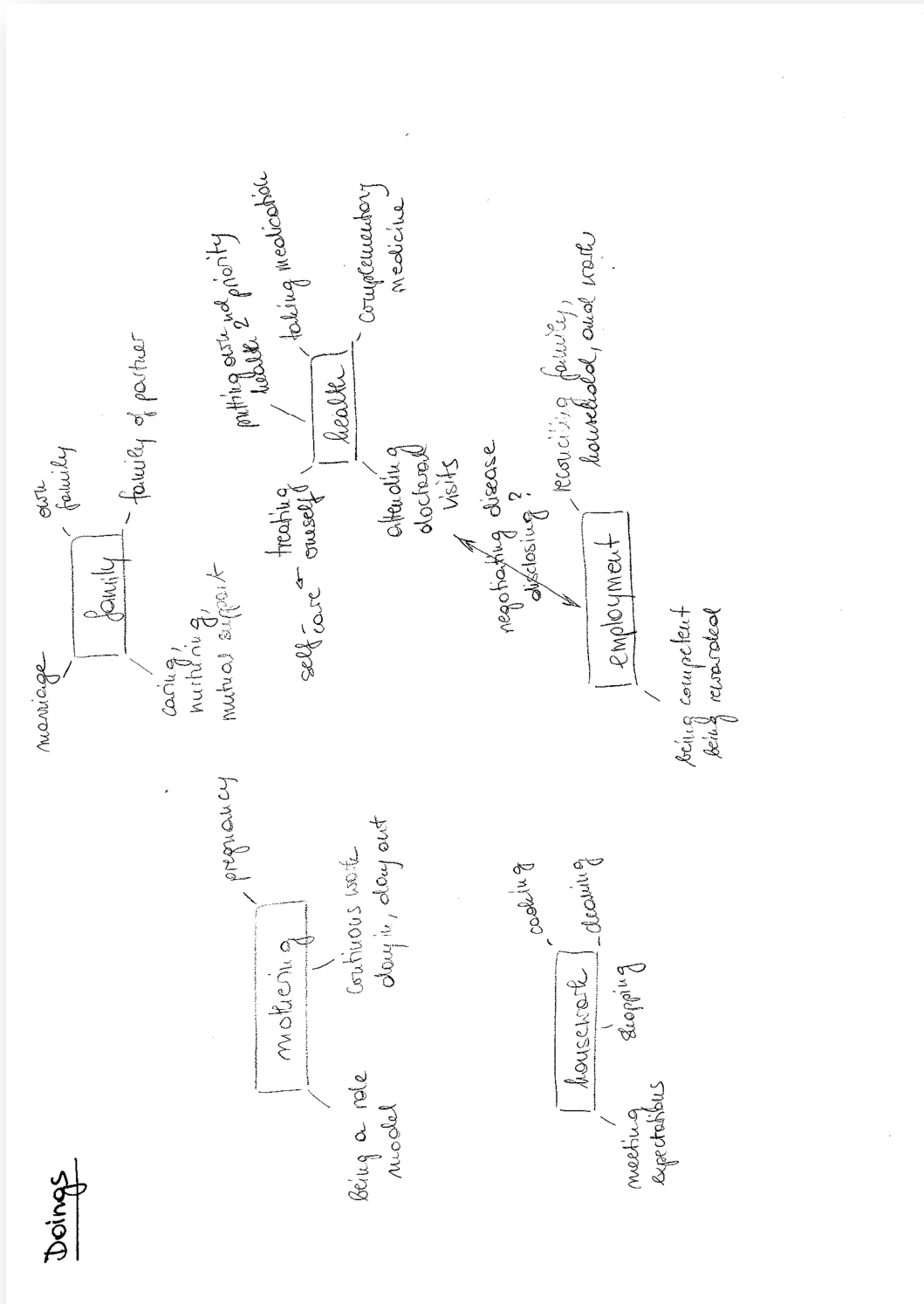
I would show the text to the woman and explain her, how I think the texts influences/relates to her doings and subsequently ask the informant to elaborate on my understanding.

What do you think about the wording of the texts? Are there a lot of technical terms used in the text? How did you get to know what these terms mean?

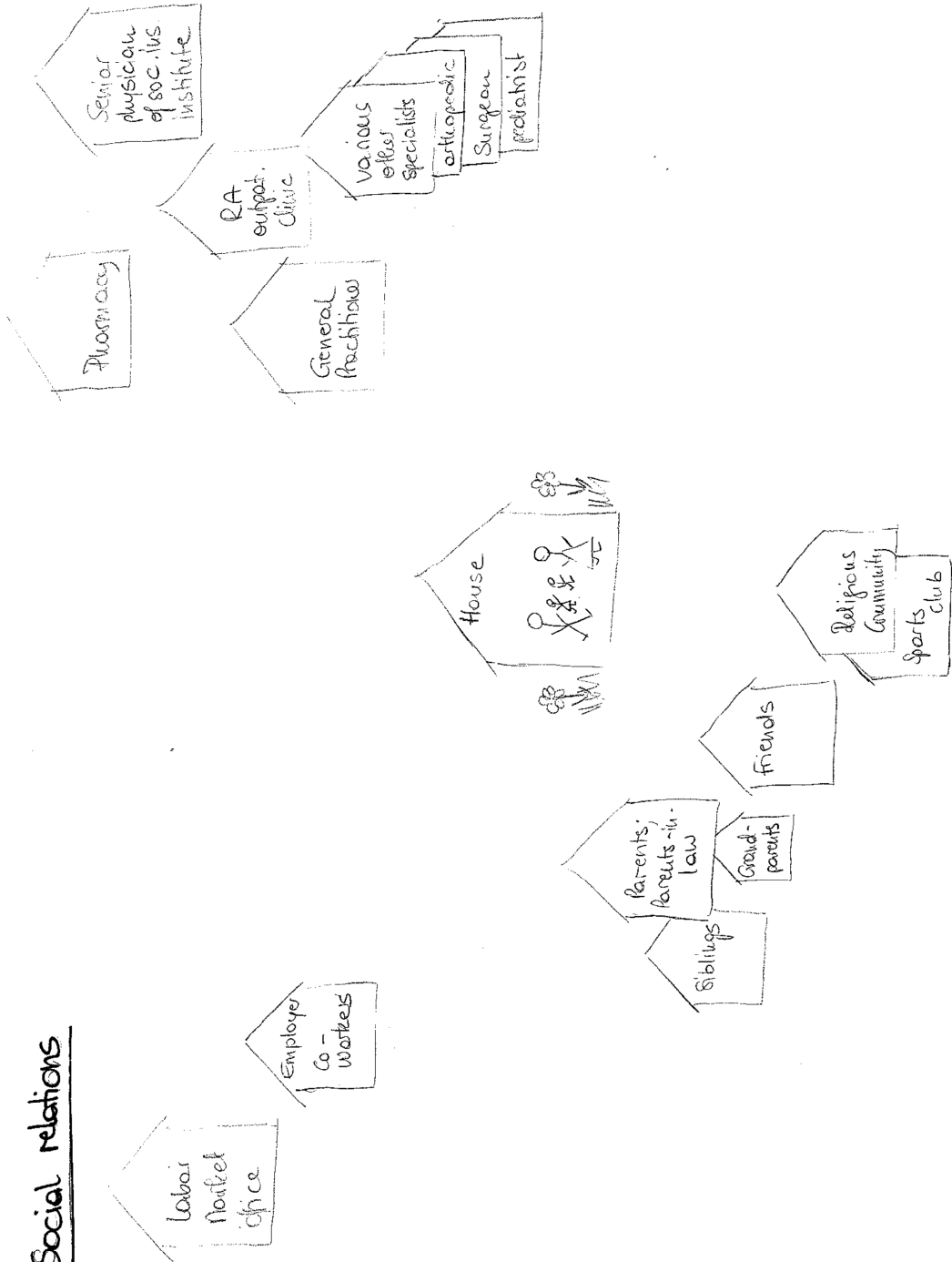
If it is a form to be filled in:

Do you mind if we have a brief look through the questions together? Can you tell me what information is required for you to fill in this form? In order to fill the form in, do you have to look up some information, can you freely respond to the questions? Is there anything which you would change in this form? If so, what and why?

Appendix 3: Examples of mind maps



Social relations



Appendix 4: Question guide for participant observations

[this is the translation of the German guide]

[These questions will depend on the occasion where the participant observation takes place; however, the proposed guide will give some information about the nature of the questions which will be asked.]

I try to exactly recall the sequences of what you just did [I would talk out the sequences].

Did I get it the right way?

Would you mind if we take a couple of minutes and you draw a map of how you see the sequences being related to each other?

Why are you carrying out what you just did in this order?

If you were going to make any changes in the process of what you just did, how would you change it; what would you change?

When doing [what informant just did], is there anything that is not available to you, but where you think, it would make it easier if you would have it?

What does coordinating your doings with the doings of somebody else add to your doings? In what ways do these interactions facilitate your doings or complicate them?

Would doing [what informant just did] look different at another day? What would be different?

Do you sometimes get a hand in doing [what informant just did]? If so, who would do so? How does it change what you do?

[Throughout the research process, I as the researcher may start to draw maps about my image of the social relations. I would bring the 'map' with me to the next meeting with the informant and would show it to and discuss it with the respective woman. The following questions may guide this discussion:]

I started to draw a map on how I see your doings coordinated with each other as well as with other people based on our previous meetings and the time I observed you when you were engaged in your doings.

What do you think about this map – would you agree that it reflects how you do things? Are there any things you would add or remove?

Is there anything you would have not thought about that way?

Is there anything you would like to alter in the way you do things? If so, how would you like to be the map different than it currently is?

Appendix 5: Guide for field-journal

[this is the translation of the German guide]

What did the woman do?

With whom did she interact? How did she interact with others?

For which purposes did she engage with others?

How did she sequence her work?

Did it happen naturally or did she explicitly organize/coordinate it that way?

Did she perform various work simultaneously?

Was there anything that was surprising or unexpected to me?

Appendix 6: Ethics Approval notice



Office of Research Ethics

The University of Western Ontario

Website: www.uwo.ca/research/ethics

Use of Human Subjects - Ethics Approval Notice

Principal Investigator: Dr. L. Shaw

Review Number: 17117E

Review Date: May 14, 2010

Review Level: Expedited

Approved Local # of Participants: 0

Protocol Title: Coordinating the occupations of everyday life as a mother with rheumatoid arthritis (RA) in Austria: A qualitative study.

Department and Institution: Health & Rehabilitation Sciences, University of Western Ontario

Sponsor:

Ethics Approval Date: June 03, 2010

Expiry Date: June 30, 2013

Documents Reviewed and Approved: UWO Protocol, Letter of Information and Consent (ver 1.4, May 27/10)

Documents Received for Information:

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced study on the approval date noted above. The membership of this REB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the UWO Updated Approval Request Form.

During the course of the research, no deviations from, or changes to, the protocol or consent form may be initiated without prior written approval from the HSREB except when necessary to eliminate immediate hazards to the subject or when the change(s) involve only logistical or administrative aspects of the study (e.g. change of monitor, telephone number). Expedited review of minor change(s) in ongoing studies will be considered. Subjects must receive a copy of the signed information/consent documentation.

Investigators must promptly also report to the HSREB:

- a) changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
- b) all adverse and unexpected experiences or events that are both serious and unexpected;
- c) new information that may adversely affect the safety of the subjects or the conduct of the study.

If these changes/adverse events require a change to the information/consent documentation, and/or recruitment advertisement, the newly revised information/consent documentation, and/or advertisement, must be submitted to this office for approval.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

Chair of HSREB: Dr. Joseph Gilbert
FDA Ref. #: IRB 00000940

Ethics Officer to Contact for Further Information

Janice Sutherland

Elizabeth Wambolt

Grace Kelly

Denise Grafton

This is an official document. Please retain the original in your files.

cc: ORE File

Appendix 7: Letter of information and consent form

Information letter for research participants

„Coordinating the occupations of everyday life as a mother with rheumatoid arthritis (RA) in Austria:
A qualitative study.“

To whom it may concern,

We would like to invite you to participate in a qualitative study with interviews and participant observations.

Participation in this study is voluntary. You can withdraw your consent to participate in this study at any point in time without the need to indicate reasons for your withdrawal. Withdrawal from this study will not have any influence on your further treatment.

Please sign the informed consent letter only

- if you were able to comprehend the nature and process of this study
- if are prepared to agree on participating in this study
- if you are well aware of your rights as participant in this study

For this study, the information letter and the informed consent form, ethical approval was given by the responsible Research Ethics Boards.

1. What is the background of this study?

Several studies have already been conducted to examine the impact of chronic diseases on the daily occupations of patients. This study aims to gain better understanding on how your occupations as a mother with rheumatoid arthritis are shaped by the social and political context in which you are embedded in. In particular, we are interested in which occupations you perform where and when in your daily live, in which sequence and with which support. We then want to examine how your occupations are shaped by social and political Austrian norms and values. For instance, motherhood, or living with a chronic disease is associated with certain norms and values. In this study we want to explore whether these norms and values influence your daily occupations.

2. What is the aim and purpose of this study?

The aim of this study is to explicate how mothers with rheumatoid arthritis coordinate their daily occupations and how these occupations are shaped by the social and political context in which they are embedded in. For this study, we are looking for women who are diagnosed with rheumatoid arthritis, aged between 25 and 45, and have a child that has not yet attained age of consent.

3. How will the study be conducted?

In the frame of this study, two interviews and up to four participant observations will take place. The interviews take place in a quiet room either at the outpatient clinic of the Department of Rheumatology of the general hospital in Vienna (Floor 6), or if you prefer at your place. Each interview will last between 1 and at maximum 2 hours. In the first interview you will be asked to talk about your occupations which you perform on an ordinary day. You then would be asked following up questions based on the topics which came up in the interview.

In between of the first and second interview up to four participant observations will be conducted (depending on how much additional information will be required). With your consent further meetings will be allocated at the end of the first interview. Throughout the participant observations the participant observer will take notes about how you coordinate your occupations, when and how you engage with other people, whether you interact with any texts (such as forms and information letters) and how these texts influence your occupations. Throughout the participant observations other family members or acquaintances might be present. You are asked at the beginning of each meeting to consent to the presence of the researcher, as well as other people present will be also asked for their verbal consent. Throughout the interviews and participant observations you might refer to or use texts and documents such as forms to be filled in, hospital charts, and various information letters that would be included into analysis as well. The second interview will be performed after the participant observations. The texts which became relevant in your daily occupations will be discussed. The researchers are particularly interested in how the identified texts bear values and beliefs that are relevant within your social and political context and subsequently, how these texts impact your daily occupations. Throughout the entire data collection, the primary researcher keeps a journal of her thoughts and observations that will also become part of the data set for analysis.

Meetings will be scheduled with the responsible researchers for this study who will also conduct the interviews and participant observations. The interviews will be audio-taped and transcribed verbatim. Right from the onset of the taping of the interview all data and also the further analysis will be saved and treated anonymously. Also the notes taken throughout the participant observations will be treated anonymously.

The insight gained from your daily occupations will contribute to a better understanding of how your daily life as a mother and person with rheumatoid arthritis is coordinated by means of various regulations and interactions with different people. No known risks or harm for you as a research participant are associated with the study. You can decide where and when you would like to engage with the researcher and you are encouraged to choose a place and time that is comfortable for you.

4. What is the time expenditure for this study?

The two interviews will last each approximately 1 to maximum 2 hours. The first interview will take place at the beginning of the study, the second at the end. In between the two interviews up to four participant observations will be conducted. The participant observations will last from 2 to maximum 8 hours (during waking hours). The time and duration of the participant observation will be arranged according to your preferences. Light refreshments will be provided throughout the interviews. Overall, the data collection period will last up to 12 weeks.

5. Do cost arise due to participation in this study? Is reimbursement for costs available?

Due to participation in this study, no additional costs should arise for you. However, in case the interviews take place at the Medical University of Vienna, you would become reimbursed your travel-costs.

6. How will the data collected in this study be used?

The data which will be collected in the frame of this study will be treated confidential. Only the responsible researchers for this study in Vienna will have access to the confidential data. These persons are liable to confidentiality. In case of reasonable suspicion of child abuse, the responsible researchers for this study have to make a report to the responsible authority according to the law (§ 54 Ärztegesetz).

This study will be published as scientific paper. All findings will be presented in an anonymous form. You will be informed about the findings of the study, if you would like so. Once data is collected it will be assigned with an identification code. The master list linking participants' data to their identification codes will be stored in a separate locked file cabinet here at the Medical University of Vienna. For review, analysis and publication data will be translated into English. Data translated in English will be taken to The University of Western Ontario, Canada for purposes of analysis, but the master list will remain at the Medical University of Vienna.

Representatives of The University of Western Ontario Health Sciences Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research.

7. Name and availability of responsible researchers for this study

The Medical University of Vienna
Department of Internal Medicine III, Division of Rheumatology

Mrs. **Birgit Prodingler**, PhD Cand., MSc

PD Dr. Mag. **Tanja Stamm**, PhD, MSc, MBA

Ao. Univ.-Prof. Dr. **Klaus Machold**, Rheumatologist

INFORMED CONSENT FORM

„Coordinating the occupations of everyday life as a mother
with rheumatoid arthritis (RA) in Austria:
A qualitative study.“

I have read the letter of information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction. I received a copy of the information letter.

All the information related to the study process was comprehensively explained to me in a meeting with _____. I was provided with sufficient time to ask questions and received adequate response.

I agree in participating in this study.

I am aware that this study will be published as a scientific paper. My rights as patient for anonymity and confidentiality will be warranted.

	Participant	Responsible researcher for the study
Date		
Name in print		
Signature		

(The study participant receives a copy of the signed letter of information and informed consent form; the original remains with the responsible researchers for this study.)

Curriculum Vitae

Name: Birgit Prodinger

Post-secondary Education and Degrees: School of Occupational Therapy
Salzburg, Austria
2001-2004 Diploma in Occupational Therapy

European Master of Science in Occupational Therapy Program
Hogeschool van Amsterdam, The Netherlands
2005-2007 M.Sc. in Occupational Therapy

The University of Western Ontario
London, Ontario, Canada
2008-2012 Ph.D. Health and Rehabilitation Sciences

Honours and Awards: School of Graduate and Postdoctoral Studies
Graduate Scholarship (2008-2012)
Graduate Thesis Research Award (2011 & 2012)
Scholarship for participation in European Network for Social Policy Analysis (ESPAnet; sponsored by the European Commission) (2011)

Related Work Experience Faculty member (part-time)
University of Applied Sciences in Salzburg, Austria
Department of Occupational Therapy
2011-2012

External lecturer
University of Applied Sciences in Vienna, Austria
Post-graduate program in Occupational Therapy
2010 – 2012

Teaching Assistant
The University of Western Ontario, Canada
School of Occupational Therapy
2008-2012

Research Trainee for Dr. L. Shaw
The University of Western Ontario, Canada
2008 – 2012

Occupational Therapist
The Medical University of Vienna, Austria
2007 – 2008

Publications:

Prodinge B, Shaw L, Laliberte Rudman D & Townsend E (2012): Arthritis-related occupational therapy: Making invisible ruling relations visible using institutional ethnography. *British Journal of Occupational Therapy*. (Accepted for publication).

Prodinge B & Stamm T (2011). The emergence of Occupational Science in Austria: An insider perspective. *Journal of Occupational Science*, Early online. DOI: 10.1080/14427591.2011.582833

Prodinge B & Stamm T (2010): Self-reflection as a means for personal transformation: An analysis of women's life stories living with a chronic disease. [38 paragraphs]. *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research*, 11(3), Art. 6, <http://nbn-resolving.de/urn:nbn:de:0114-fqs100363>

Stamm T, Machold K, Smolen J & **Prodinge B** (2010): Life stories of people with rheumatoid arthritis: how gender and other contextual factors shape their everyday activities. *Musculoskeletal Care*, 8, 78-86.

Oral presentations:

Prodinge B (2012): The organization of the production of hospital records of women with rheumatoid arthritis (RA). *Congress 2012 of the Humanities and Social Sciences* (Waterloo, Canada).

Shaw L, **Prodinge B** & van Bruggen H (2012): Future trends in European work practice curricula. (In-conference workshop) *COTEC Congress of Occupational Therapy*. Stockholm, Sweden.

Prodinge B & Sontag C (2011): Using an occupational science perspective to shape human societies – Making our distinct perspective explicit. *Occupational Science Conference: OTs owning occupation*. Plymouth, UK.

Prodinge B, Shaw L, Agocs C, Laliberte Rudman D & Stamm T (2011): Using critical feminist theories to advance knowledge about the occupations of mothers living with rheumatoid arthritis. *Conference of the Canadian Association of Occupational Therapy*. Saskatoon, Canada.

Laliberte Rudman D, Shaw L, Hartman L, **Prodinge B** & Zur B (2011): Possibilities for graduate training in occupational science. (Panel discussion). *Conference of the Canadian Association of Occupational Therapy*. Saskatoon, Canada.

Prodinge B, Shaw L & Laliberte Rudman D (2010): Application of a critical feminist theoretical framework: Broadening the study of everyday occupation. *Joint Conference of the Society for the Study of Occupation: USA (SSO:USA) and the Canadian Society of Occupational Scientists (CSOS)*. London, Canada.

Prodinge B & Stamm T (2010): Exploring occupations of people with hand osteoarthritis – A European qualitative multi-site study. *Symposium of the Society for the Study of Occupation - Multi-Site Institute*. London, Canada.

Prodinge B (2010): Using critical feminist theories to advance the knowledge on the daily lives of women with disability. *Concepts of Health, Illness and Disease Multidisciplinary Conference*. Bristol, UK.

Prodinge B & Dennhardt S (2010): Studying 'occupation' where the grass is greener? Internationalized accounts of occupational therapy knowledge. (In-conference workshop) *Conference of the World Federation of Occupational Therapy*. Santiago de Chile: Chile.

Poster presentations: **Prodinge B**, Shaw L, Laliberte Rudman D & Stamm T (2012): The need for a cross-sectorial approach to facilitate work and social participation of women with rheumatoid arthritis. *Congress of the European League against Rheumatism*. Berlin, Germany.

Carrier A & **Prodinge B** (2012): Understanding ruling relations: Institutional ethnography's contribution to occupational therapy practice. *Canadian Conference of Occupational Therapists*. Quebec City: Canada.

Invited presentations: **Prodinge B** (2012): Future challenges for health professionals; communication across health care levels. *Congress of the European League against Rheumatism*. Berlin, Germany.

Prodinge B (2011): Extended roles from different perspective: possible benefits for patients, professionals and the health care system. *Congress of the European League against Rheumatism*. London, UK.