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**Narrative in action:
Meaning-making in everyday
activities of women living with
chronic rheumatic conditions**

Thesis for the degree of Philosophiae Doctor

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Norwegian University of Science and Technology
Faculty of Social Sciences and Technology Management
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ABSTRACT

Narrative in action: Meaning-making in everyday activities of women living with chronic rheumatic conditions.

The overall aim of this thesis was to contribute to an understanding of the everyday life of women with chronic rheumatic conditions with an emphasis on how they relate to narrative meaning in their everyday activities. The design conveys an ethnographic approach, including a thorough consideration of conceptual and empirical resources. Narrative traditions were explored as well as existing knowledge of everyday activities. Following on from this exploration, an epistemology and methodology was traced to study 'meaning in action' for women living with chronic rheumatic conditions in their local cultures. The findings further show how meaning in action happens in the everyday activities of the participating women. By engaging in their local cultures the women enabled themselves to communicate significant issues of meaning through everyday activities. This thesis contributes to the existing knowledge of everyday living with chronic rheumatic conditions by that it has established a conceptual framework of 'narrative in action' and subsequent methodology to study the phenomenon. Further it has shown how everyday action provides interpretative possibilities that enable the women to manage, adjust and negotiate their meanings. The concept of 'enacted ordinariness' is established and it is shown how questions of moral worth is embedded in everyday action and how society's labelling tradition impacts the women's everyday living. Participation in everyday activities in local cultures is found to be of great value for the women but several contradictions are embedded. Processes of meaning are managed in their everyday action, and they do not set their condition apart from themselves and their way of living. Suggesting that activities produce interaction and communication between individual practices and cultural practices, this thesis also contributes to the ongoing exploration of the concept of occupation/activity. For occupational therapy and occupational science this thesis adds to existing basic knowledge of the temporal quality of activities and their relatedness to narrative and meaning.

Key words: chronic illness, everyday activities, narrative methods, focused ethnography, participation

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List of papers

A:

Staffan Josephsson, Eric Asaba, Hans Jonsson & Sissel Alsaker (2006): Creativity and order in communication: Implications from philosophy to narrative research concerning human occupation. *Scandinavian Journal of Occupational Therapy* 2006 13:86-93.

B:

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D:

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Preface

The women participating in this study were engaged in their local cultures. They acted, participated, worked, suffered and enjoyed adventures of everyday life recognisable in and connected to “a good and meaningful life” in their local cultures. This thesis focuses on how these four women related to meanings in their everyday activities, regardless of their conditions, symptoms or biomedical labels.

The women participating are diagnosed with Chronic Rheumatic Conditions (CRC) and live their everyday lives at home. They represent a broad spectrum. They are of different ages, engage in different activities, have different biomedical diagnoses, and differ in severity of symptoms. They were found to possess powerful voices, voices that expressed in their everyday existence the ambiguity of always being both ordinary and special. They had income, but few colleagues; they had chronic conditions, but looked healthy; they were mothers and partners, but also patients; and they did ordinary activities in their everyday lives, but questioned the moral value of their ordinariness.

In my approach to these four women and their everyday lives, I position myself at the intersection between health science, occupational science (OS) and the profession of occupational therapy (OT). My professional experience in OT, both as a therapist and teacher has extended over thirty years, and my academic experience has developed over the past ten years. Belonging to the OT community for so many years has established a profound belief that participating in everyday occupation represents a resource that people can draw upon. This resource provides individuals with the power and opportunity to experience, manage, sustain and confirm both existential and practical issues of living, and by extension to promote health, well-being and meaningful living. Further OT derives its knowledge base from a blend of biomedicine and social science, acknowledging the individual as simultaneously embodied and social, where the blending takes place through the actualization of issues of meaning in action. Taking such a perspective implies that meaning is closely connected to everyday activity. In our society meaning is closely connected to the purpose of living and thereby to the image of a ‘good’ and healthy life. However, this common understanding of the good life does not include illness and disease, and thereby society ascribes moral value to chronicity. Consequently this thesis has to navigate through difficult waters in addressing chronic rheumatic conditions (CRC), in adopting labels and norms, as well as in blending biomedicine and social science.

Additionally I realise that there was only limited knowledge of how meaning was 'made' of everyday life by those with a chronic condition (Alsaker & Josephsson, 2004) and I wondered how the women in this study, Lily, May, Esther, and Vivian, managed and related to everyday meanings. How did they enact meaning or the 'good' in their everyday activity situations?

I recognise the dilemma of focusing on the opportunities and resources available to people with the label CRC and subsequently compared to societal norms and to average ability in our culture, where health is primarily understood as being free of disease. However, my experience as a therapist has given me reason to believe that a 'good' life can also be lived by people with chronic conditions. My hope is that this research will contribute to widening the way meaning is related to health and well-being in the everyday lives of women living with CRC.

Part I – general overview

Women living an everyday life with Chronic Rheumatic Conditions

In Norway, which has a total population of 4.5 million people, women with CRC number close to half a million, and they are apparently as diverse as the population as a whole (Kvien, 2004; 1992). Their condition has a negative impact on their everyday lives, to judge by their self-reported quality of life (Alonso, et al., 2004; Poole, Chiappisi, Cordova, & Sibbit, 2007), but also restricts their expected time of survival by close to ten years (Kvien, 2004). Research studying their situation and everyday life shows how they experience their conditions (Charmaz, 2002; Råheim & Håland, 2006), adapt to their symptoms (Goodacre, 2006; King, Willoughby, Specht, & Brown, 2006), and develop a variety of coping strategies providing themselves with a manageable daily life (Mendelson, 2006; Persson, Berglund, & Sahlberg, 1999; Skuladottir & Halldorsdottir, 2008; Sutton, Gignac, & Cott, 2002; Yoshida & Stephens, 2004). They also have to make changes in or reconstruct the way they go about their everyday activities (Birkholtz, Aylwin, & Harman, 2004; Dubouloz, Laporte, Hall, Ashe, & Smith, 2004; Sutton, et al., 2002) as well as how they ascribe value to their way of living (Delmar, et al., 2006). Existentially CRC impact the individuals' sense of self, in that they experience changes in role and status and are affected by the subsequent identity issues (Alsaker, 1998; Alsaker & Josephsson, 2004; Kralik, Koch, Price, & Howard, 2004; Townsend, Wyke, & Hunt, 2006). Affected is also their participation in society and the way they experience their status as citizens (Boonen, 2005; Jakobsen, 2004). Individuals with CRC generally have low participation in the work force and many women in particular live from their disability pension (Frerer & Vu, 2007; Lillefjell, 2008; Mau, Listing, Huscher, Zeidler, & Zink, 2005). They live their everyday lives with family and friends, but they regularly consult a variety of professional experts such as medical doctors, physiotherapists, occupational therapists to get the services and treatment they need (Steultjens, et al., 2002). We have limited knowledge of the everyday activities they participate in, of when and how they take part, and knowledge about how they relate to meaning in their life and activities is equally limited (Keponen & Kielhofner, 2006; Law, 2002; Steger, Frazier, Oishi, & Kaler, 2006).

CRC is a label chosen to denote a diagnostic diversity (Badley, 2008) for the scope of this thesis. There is no agreed label for this group of people in the literature, and scientists use broad terms about people with chronic conditions and/or chronic illnesses or with a disability

(Hydén & Sacks, 1998; Paterson, 2003). When differentiations are made, the biomedical approach uses diagnoses and the social science approach uses chronic illness or diseases. Chronic rheumatic conditions are not a precise diagnostic label but comprise a wide variety of diagnoses, with Rheumatic Arthritis (RA), Arthritis and Fibromyalgia being the most common and well-known (Cooper, 2003; Marks & Allegrante, 2007; Sangha, 2000).

People with CRC do, however, have a whole range of symptoms and experiences in common that affect their way of living, such as recurrent pain in joints and muscle tissues, fatigue and restricted body movement. They are usually on daily medication to reduce these symptoms, and many need recurrent surgery to prevent distortions in joints, to reduce pain, or to enhance their movement. These conditions are seen to place heavy burden on the individual and on society, both personally, socially and economically (Cooper, 2003; Kvien, 2004; Marks & Allegrante, 2007; Sangha, 2000; Werner, Isaksen, & Malterud, 2003). The conditions also bring about a variety of physiological changes, which are due both to the disease and to side effects of medication. For the individual these aspects are present in varying ways throughout their life course after the onset of disease. Onset also varies from early childhood to late in life. For example, worldwide the incidence of RA is said to be 0.4-1.0 percent of the world population with women being most affected (Kvien, 2004; Sangha, 2000). In Norway this means 800,000 people, and, if we take it that 60 % are women, this would mean 480,000. These authors also report that recent decades have seen a raise in survival rate for most medical diagnoses due to improved medical treatment. This is not the case for people with, for example, RA. Their life expectancy has not improved over the past 40 years, and they continue to lose 6 to 10 years of life on average compared to the rest of the population. The aetiology of the diseases is only partly known, and sufferers cannot be cured bio-medically but can be considerably assisted by medication and surgery to ease symptoms and provide for better everyday function.

Another issue of importance for this thesis is the fact that health and social sciences' are identifying women with CRC as being different from the so-called 'normal' population. They are labelled as disabled, handicapped, as having chronic diseases or illnesses, all labels that distinguish them from the normal population, implying that they are different and thereby creating expectations that they are "not able to" do what everyone else do as regards work, self-care and participation in society in general (Boonen, 2005; Townsend, et al., 2006).

In summary these women live their everyday lives with conditions that have implications for almost all areas of living, the pain of their bodies determining when they can participate and when they must rest and thereby affecting their commitment and their

enthusiasm for life. On the other hand society's way of labelling their conditions and thereby identifying them as different from the general population establishes an ambiguity regarding their experience of belonging to and their ability to provide valuable input for society.

Conceptualisations and approaches

Exploring meaning in the everyday activities of women with CRC draws upon certain core concepts and approaches, which are addressed in the following. Central among these are the concept of 'everyday activities' and the approaches that follow from it, alongside concepts of 'meaning' and 'narrative'.

Everyday activities

Culture

The concepts of 'everyday life' and 'everyday activities' are rarely defined in the literature but are often used interchangeably. When used in OT, the term 'everyday activities' generally means what individuals do as time is passing (Hasselkus, 2006). Also included in the profession's use of the term is how individuals perform, where they perform and the assumption that such activities are embedded with meanings.

Scientific approaches to the area of everyday activities are connected to a notion of 'everyday life'. They are relatively few and did not appear in the social science literature until the 20th century, even if some philosophers had previously talked about everyday practice or pragmatism (Lawlor, 2006; Polkinghorne, 2004; Pollio, Henley, & Thompson, 1997). Based on Schüts's ideas of the social interaction in everyday life (Borg, Runge, Tjørnov, Brandt, & Madsen, 2007), however, Berger & Luckman's (Berger & Luckman, 1967) theories of the dialectic between the individual and society came to have considerable influence. Concepts of everyday life were developed, as in Goffman's "The Presentation of Self in Everyday Life" (Goffman, 1992), which are widely used in health and social sciences. This knowledge recognized everyday life as a scientifically interesting subject of study and produced results showing how structure and content characterized everyday life and describing what kind of importance and values people ascribed to it. Gullestad (1996) understood everyday life as social acts (Gullestad, 1989, 1996) happening in a culture. She posed that culture in itself is not a set phenomenon but is created, adjusted, and negotiated by acting people in what she called 'local circumstances'. This thesis uses the term *local culture*, a phrase commonly used in literature but not conceptualised. Here it is used to characterize the experience of everyday

life in specific, identifiable localities, in contrast to global cultures in which the phenomenon of everyday life is identifiable globally in many geographic localities (Frerer & Vu, 2007; Gubrium & Holstein, 1997). Local culture comprises ordinary people's interpretation of what and how to act in the circumstances of their everyday living and their moral values and interests, their feelings of appropriateness and comfort.

Culture and its content of 'everyday social acts' are thus viewed as 'ongoing' and continuously changing, which contrasts with a view of culture as something set or clearly framed (Gullestad, 1996). Consequently 'everyday life' contains what people do on their ordinary days, individuals who at any time are considered to be the general population in a culture.

Recently everyday life has become highly topical in general publications in Scandinavian culture, allegedly due to our welfare state, where almost everyone belongs to the class of 'ordinary' people with everyday lives. The idea of ordinariness used in this thesis has its origins here and represents a normative or general understanding of a culture/population's everyday life. Inherent to it are the activities and the practical and moral aspects temporally ascribed to the idea of ordinariness (Kralik, 2002). Gullestad (1996) states everyday life to be "people's ways of establishing integration in their immediate life world by setting up and maintaining a meaningful connection between social roles, activities and circumstances", an understanding which this thesis draws upon. However, from her reasoning follows that the ordinariness of everyday life might be different for people not belonging to the general population, a question of relevance for individuals living with CRC.

Activity

It is also of relevance for the scope of this thesis to clarify the concept of activity. Historically the profession of OT drew its basic knowledge from biomedicine, psychology, health and social science, creating activity-based clinical interventions as means and goals of treatment (Kielhofner, 1997; Ness, 2002; Price & Miner, 2007). Student education took place through skilled role models and socialization in the practice settings of hospitals and community care. Historically both activity and occupation have been used in OT literature (see Ness, 2002 for a review), but the scientific concept use did not emerge in the profession's conceptual foundations until the 1980s when Kielhofner (1985), for example, published *A Model of Human Occupation (MOHO)* and *Occupational Science* flew the nest (Clark, et al., 1991; Yerxa, et al., 1989). In these conceptualisations, occupation was the idea on which the profession was to ground and develop its interventions and build a scientific knowledge base.

The Model of Human Occupation (Kielhofner, 2002) understands occupation as an ongoing dynamic interlude between the environment, the person and the performance. The variables in the model are based on existing knowledge on how the environment facilitates and constrains opportunities for occupation, how people's actions are motivated, and how the body works cognitively, emotionally, and physiologically. The understanding of individual performance is in this model based in these notions and produce occupation (Kielhofner, 2002). Occupation takes place in a context and is considered to be oriented towards the future (teleological), but where previous experiences are included in individual ways when individuals are acting (Mattingly, 1998a).

From then on 'human occupation' became a research focus for academically oriented OTs, developing knowledge of OT assessment and interventions (Kielhofner, 2006). A community of OT scholars (Clark, 1993; Zemke & Clark, 1996) proposed that the phenomenon of human activity/occupation could be studied in a disciplinary framework and produce general knowledge for society as a whole, rather than simply developing knowledge to expand OT's knowledge base and raise the profession's credibility. Building a knowledge base, meant studying the phenomenon of occupation according to form, function and meaning (Zemke & Clark, 1996). Today scholars both in OT and OS contribute to a rapidly growing knowledge base (Hocking, 2000) studying occupation/activity. The emphasis is on conceptualizing and creating an empirical base for the connectedness of people's occupations to cultural meaning and values, to habits and routines, to health-promoting qualities (Clark, 1993; Wilcock, 2006, 2008; Yerxa, 2002), and to the ongoing quality of occupation (Pierce, 2001a). The OT profession's historical base in the therapist's experience and clinical observations of the transforming power inherent in occupation (Zemke & Clark, 1996), are thus developing a scientific base. This base comprises both evidence of clinical interventions and explorations of related concepts and phenomena, upon which this thesis draws. Today clinicians and scholars use the concepts of both occupation and activity (Kielhofner, 2007; Pierce, 2001b), and there is no agreed and unified use of concepts. In this thesis activity will be used when not referring to specific authors.

Based on these notions, this thesis understands 'everyday activities' to be the everyday doings of people in their local cultures and/or cultures. This implies that communication is ongoing within a general culture, both socially and materially (Gullestad, 1989, 1996). Additionally, due to the mundane and repetitive quality of everyday life and activities, we need to consider that day-to-day activities provide the individual with experiences, habits and routines that establish structure and predictability for the individual and allow for novel

experiences and experiments such as creative endeavours (Clark, 2000; Dubouloz, et al., 2004; MacKinnon & Miller, 2003). This implies that this thesis consider everyday life to be where cultural acts (Gullestad, 1996) go on, and where everyday activities mean acting in a temporal and cultural world. Women with CRC live and act here, too, and so their options for activities are contrasted to a normality that is taken for granted and where meaning is inherent. We have only limited knowledge about how these women perform their everyday activities and how they relate to meaning.

Meaning

The idea that something has meaning or is meaningful is widely used in the literature. However, what meaning is or means is difficult to understand as it is rarely defined. When used, it is frequently connected to an individual's experiences in activity, chronic illness and everyday life (Bruner, 1990; Dubouloz, et al., 2004; Frankl, 2000; Steger, et al., 2006; Thorne, 1999).

In general the concept has something to do with an 'end result', such finding meaning in life or experiencing meaningfulness when participating in certain activities (See Steger, et al., 2006 for a review). From OT we are familiar with the idea of 'meaningful occupation', which is central in the profession's conceptual framework and in the overall aim of intervention, but the profession also argues that it is where the 'therapeutic power' resides (Kielhofner, 2008). Consequently, meaning is closely connected to motivation, in that, if a person is to be motivated to take an action, that action has to have some kind of meaning to the individual. Motivation is understood as intrinsic or extrinsic, concepts borrowed from motivational psychology, where the motivational force is connected to individual or environmental values (Kielhofner, 1985). Recent editions of MOHO use narrative theory to explain and understand motivation and meaning, by bringing in narrative slopes (Gergen & Gergen in Kielhofner, 2002). Here, when interpreting his/her temporal activities in a plot structure, the individual establishes meaning by telling stories.

Existential psychology tells us of "man's search for meaning" (Frankl, 2000), suggesting that humans are characterized by a "will to meaning", an innate drive to find meaning and significance in their lives, and that failure to achieve meaning results in psychological stress. According to Frankl (2000) this search for meaning is going on continuously in everyday life and activities and without this search life becomes meaningless and without direction. Here meaning is not an end result, but the search for it has an overall presence in individual lives and is thus ongoing in everyday life. Contributing extensively to

how meaning is understood, Bruner explored the human mind and meaning, introducing culture as a variable from which meaning develops. He argues that action is central in cultures and that this affects the making of meaning (Bruner, 1986, 1990). Meaning is embedded in a society or culture in the form of stories and metaphors, from which moral, meanings and habits are derived.

Steger (2006) et al. conclude their extensive review by claiming that meaning is regarded as crucial in human life, but that is difficult to assess by questionnaires, though there are several in use (See Steger, et al., 2006 for a review). The authors call for additional research to explore and refine the understanding of the construct. Their proposed definition of meaning in life is “the sense made of, and significance felt, regarding the nature of one’s being and existence” (pp 81).

Though the literature reviewed above addresses meaning in a variety of ways, a clear distinction is made between “sense-making” and “existential meaning” (Mattingly, 1998a). Sense-making is the logical way of understanding words and sentences. Existential meaning denotes something that has an explicit value for people. In OT ‘meaning’ and ‘meaningful’ refer to the existential understanding of meaning, often expressed as hope or longing, forming motivational forces that connect individuals to overall meaning in life (Mattingly, 1998a). When individuals experience illness, loss or some chronic condition, it is often to be crucial for them to have hope that enables them to imagine a future, as this makes it possible to cope, to adapt, or to manage severe and dramatic situations and changes. Examples are found in the literature of how people with hope manage life-threatening illnesses, or the loss of a spouse or a child, in a healthier way than those unable to sustain hope (Mattingly, 2006). Hope may be connected to religious images and faith, but also to clients’ overall approach to life and living in a more existential sense (Charmaz, 2002; Mattingly, 1998b). In narrative theory hope is understood as the way people make connections between their history, ongoing events and their images of possible future meaning (see Mattingly, 1998b for a review). In another narrative approach meaning is associated with the use of metaphors, which are seen to be used in everyday language to express meaning that goes beyond semiotics, implying what words cannot denote (Mattingly, 2006; Ricoeur, 1974,1991).

To sum up, meaning is considered to be crucial in human life but is difficult to grasp scientifically, both as regard its characteristics and its function. The limited research concerning meaning and women living with CRC that do exist includes surveys of Sense Of Coherence (SOC), based on Antonovsky’s model of how health is promoted and sustained and connected to meanings (Steger, et al., 2006). Surveys like this have developed general

knowledge of certain defined items that are found to be of relevance for meaning-related issues in general (Lillefjell, Krokstad, & Espnes, 2007), but they do not account for how individuals with CRC make meaning in their temporal everyday lives (Ville & Khlal, 2007). Reviewing the literature in this area showed that the main body of knowledge explored and described relations between chronic illness, meaning and everyday life (Mendelson, 2006; Poole, et al., 2007; Sidell, 1997; Thorne, Paterson, & Russell, 2003). This existing research revealed how a variety of symptoms imposed limitations on meaning relations for people with CRC, but say little about if and how limitations in meaning relations happen, how they are prevented or supported. However, reconsidering patient empowerment in chronic illness, Aujoulat, Marcolongo, Bonadiman, & Deccache (2008), show that the use of narrative research methods provides access to individual experiences of chronicity, where meaning-making processes are central to establishing coherence and meaning in their lives.

Narrative

Ricoeur (1984a) tell us that narrative is about meaning, and that narrative is the way people assemble in a coherent and understandable way the many experiences, images and incidents that they meet with when living everyday life. The concept of narrative originates from the Greek philosophers, among whom Aristotle in particular addressed the narrative function of literature and drama for the reader or the viewer (Aristotle, 1920). What fiction provided, he said, were images of significant issues for the listener, images of human affairs, of actions, thoughts, feelings; but also images of suspense, insecurity, contradiction and difficulty in the human realm. In drama, such issues are introduced, outlined and powered by suspense, until eventually a solution is provided. This mode we recognize as a complete story with a beginning, middle, and end, and an inherent plot. For the listener this provide an array of personal images, some easily recognized or connected to their own life, actions, thoughts and experiences, and this assists the individual to make order and structure but also to create new ways of understanding significant issues (Mattingly, 1998a; Ricoeur, 1984).

Using metaphors is part of this narrative mode (Ricoeur, 1974). When you do not find explicit words to express something, you chose a metaphor which denotes the essence of what you intend to express and which is named and understood in your local culture.

Narratives are widely used in health and social sciences but in many different ways. Mainly narrative is used as a method to collect and analyse verbal stories of lived experiences (Charmaz, 2002; Keponen & Kielhofner, 2006; Råheim & Håland, 2006) or as intervention in

therapy by reconstituting stories, something that facilitates change in individuals' awareness of self and identity (Charmaz, 2002; Keponen & Kielhofner, 2006; Kleinman, 1988).

Narrative research designs rarely attend to the philosophical roots, and consequently existing research does not differentiate between narrative as a concept and as a method. In this thesis narrative theory informs both the way we understand human action and the subsequent narrative analyses.

According to narrative theory (Ricoeur, 1991), stories told are stories constituted by the teller to communicate something in that moment of telling and to the listeners present. The telling of stories thus has a great transformative potential, the teller can retell, change or adjust her story at any moment in time and according to circumstances. On the other hand, stories also have a conserving potential, in that they are told and retold with the same overall themes and so constitute stability or predictability. A society's moral or cultural themes, values and habits are recognizable in fairytales and cultural sayings (Bruner, 1986, 1990; Gullestad, 1996; Yang, et al., 2007). Storytelling is thus an expression in which an individual or a culture can access significant issues regarding both stability and change, something health and social science deals with.

Aristotle (1920) wrote that narrative drama is always about human actions and their assigned significance (moral values). It is action that creates the stories, like "first she did this and then that happened from which followed...and then she did another thing and a different thing happened..." and so on. Real actions thus need to be situated in a context to take place, and consequently stories are also about where and when and how, not just about what. In this way Aristotle grounds fictional narratives in the human realm of everyday actions. Basing his work on Aristotle's arguments of narrative drama, Ricoeur (1991) proposed that narrative in real life is also closely connected to action, not solely to storied texts.

Mimesis

Action is connected to meaning through a process called *mimesis* (Aristotle, 1920; Ricoeur, 1984). *Mimesis* denotes imagination and imitation, features Aristotle thought to represent a natural urge in humans, most obvious in art, in that he thought all art forms to be imitations of something human, like form and proportions, movement or thoughts (Aristotle, 1920).

Ricoeur (1984) developed Aristotle's work on *mimesis* by connecting it to real life, seeing it as a human function consisting of three folds, establishing a link between human real life action and stories told.

Narrative in action and the function of mimesis as three folds in real life are central to the knowledge developed through this thesis, with different aspects attended to in the four papers. An outline of the three folds of mimesis is given here, assisted by the metaphor of a stream:

In mimesis 1 we localize the action. Here the activities extend, for example, over a day or a week. This ongoing everyday action may be better expressed by the metaphor of a stream, just floating along, looking the same, and never ending, but varying as regards the amount of water and debris it is carrying along. So also is everyday action when understood by the mimesis 1.

In mimesis 2 we see initial attempts to bring together or create connections between the thoughts and images produced in mimesis 1. In the stream suddenly currents or waves are visible, just for a moment, then disappear, or debris such as leaves come together and for a moment form small heaps, only to disintegrate suddenly. This initial creation of order is provisional in mimesis 2, but opens for a 'trying out' of space where images can be connected to previous experiences and create an 'imaginary' world of 'as if'. This is an interpretative process that enables the actor to 'test' provisional ways of understanding and making meaning of her experiences. Mimesis 2 provides a means to make tentative meanings out of events in the everyday stream of information and perceptions that is experienced in everyday action. This tentative or provisional quality of mimesis 2 also provides the option to disclaim or reject the connections made, and additionally opens a creative quality of playing with different ways of making connections between incidents or placing causality between odd variables. The play of 'as if' is like playing with images of possible links between events and happenings. Looking into the stream again, the play of the water shows this 'as if' function by forming and un-forming currents and waves, gathering up a cluster of leaves in the autumn or the dust of pollen in spring. Mimesis 2 is in a way powered by suspense or anticipation. How will the story come about? Does the cluster of leaves stay together or disintegrates?

Mimesis 3 is where a coherent story is presented with the classical character of beginning, middle, and end and driven by a plot. The coherent story expresses the teller's understanding of the incidents at this moment of telling. Following the stream metaphor, we now can trace the water along the shore lines, floating between rocks and roots, driven by the fall of the landscape. But we can also follow the inherent drama of how some leaves get stuck and for a long time we are kept in suspense observing the cluster of leaves and wondering if they will manage to get past all the obstacles and eventually reach the quiet pond. We now recognize a kind of order; the beginning, middle, and end driven by a plot, which

communicates the tellers' emplotted moral theme in a way that it is understandable for the listener. Of relevance for the presented process of mimesis there is a saying known from professional practice that relates to the moral aspects of chronic conditions, namely 'the struggle and suspense inherent in unpredictable conditions' (Alsaker & Josephsson, 2004; Kleinman, 1988, 1992). This saying exemplifies an overall moral plot associated with chronic conditions; there is struggle inherent and unpredictability ahead.

To sum up, the conceptual part of this thesis has outlined existing knowledge of narrative and its relation to living a meaningful everyday life with CRC. Knowledge about and approaches to narrative and meaning have also been presented, what these are, how they are explored and experienced in people's everyday life in general and among individuals with CRC in particular. Further the impact of CRC on individuals' meaning-making is outlined. A shortage of knowledge is identified regarding how women with CRC establish meaning relations in everyday activities, and this is addressed in the thesis research aims that follow.

Research aims

The aim of this thesis is to explore action in real time and possible moments of narrative meanings inherent in the everyday activity of women living with Chronic Rheumatic Conditions (CRC). From this background the following research developed, with an overall **aim of contributing to an understanding of the everyday life of women with chronic rheumatic conditions, with an emphasis on how they relate to narrative meanings in their everyday activities.**

The specific aims for each of the four papers were:

- To situate narrative as a qualitative method to explore human occupation within a theoretical and philosophical tradition and to critically reflect on possibilities stemming from such exploration (Paper A).
- To sculpt a methodology to study the “how” of meaning-making in the everyday lives of people living with CRC (Paper B).
- To explore how women with CRC relate to meanings in their everyday activities (Paper C).
- To discover how moral issues are communicated in the everyday activities of four women living with CRC (Paper D).

To address the overall research aim of this thesis, it was necessary to get beyond general theory and existing approaches and explore empirically how meaning is realised in action among women living with CRC. To approach this aim methodologically, there was a need to consider approaches that give access to women living and functioning with CRC in their local cultures, and these will be presented and considered in the following.

Methodology

Design

Addressing the overall research aim of how some women with CRC relate to meaning in their everyday life and activities, the design of this thesis conveys an ethnographic approach.

According to Hastrup (2003), an ethnographic approach includes a thorough consideration of both conceptual and empirical resources. These resources clearly situate the design in specific conceptual traditions as well as in delimited real life circumstances. Consequently the research design in this thesis was twofold. The first task was to explore on a philosophical level narrative traditions and existing knowledge of everyday activities in general and particularly in social science. This exploration is presented earlier in this thesis. Following on from this exploration, the aim was to trace the consequences for an epistemology and methodology to study meaning in action for individual women with chronic conditions. These considerations led to an empirically based study with a fieldwork approach.

Conceptual resources for methodology

The ethnographic approach that encircles this thesis required conceptual as well as empirical material (Hammersley & Atkinson, 2007; Hastrup, 2003). I have so far addressed relevant conceptualisations and existing research. In the following, theoretical resources and epistemology relevant to the overall design of the thesis are examined by considering the premises on which our epistemology is grounded (Gubrium & Holstein, 1997).

This thesis suggests that individual meaning and significance has a narrative form and quality and is embedded in action through time, though not necessary on a conscious level all the time. Further people are understood to be both individuals and participants in society through their everyday activities. From a narrative perspective human meaning-making can be understood as embedded in the ongoing flow of everyday life activities. Through the course of their everyday lives individuals act, think, interpret, and relate to themselves, to their listeners, and to the general social and material set of circumstances that comprises their local and global culture. Narratively this means that humans continuously occupy themselves in a process of making life comprehensible and directional (teleological) by establishing links and causality between prior and present experiences and actions as well as forming images of what they want from a future (Mattingly, 1998a). This view of people implies that interpretation and communication take place continuously in individual everyday activity.

People in activity are seen as leading diverse, living individual everyday lives, which is in contrast to a general normative or universal view (Polkinghorne, 2004), whereby there exist norms that include all people in activity. A universal view of human action implies that some humans are placed outside the norms and that their everyday actions are different. Consequently a diverse view of human activity means that all people are living and acting in their local cultures with or without, for example, chronic conditions. This way of viewing the human condition challenges the well-known traditions of generalizing and unifying followed by labels and norms (Atkinson, 2005; Carter & Little, 2007; Vigh, 2008). Using a universal or generalised view has led society to develop characteristics such as diagnoses, which distinguish groups of people from the main population with the inherent danger of ascribing moral worth to these categories. Characteristics and categories are useful in science and in society to keep track of and organise the great masses of information and impressions society and individuals need to process in everyday life. However, when individuals are placed in a category such as CRC, they become patients and thereby labelled in a way that places them outside the societal norms of ordinary human activity. For example, from a biomedical perspective, the category of CRC patients puts individuals with agreed symptoms, characteristics and challenges into a unified group, a group which is considered to have shared characteristics and which, therefore, require similar treatment. However, in real life, individuals with CRC are diverse, real people living and acting a real time life.

Historically such differentiations following from a universal view of human activity leads to the danger of ascribing moral value to illness and disease by generally consider them deviations from what is considered 'good' in our society (Mattingly, 1998b, 2006). Biomedicine bases its understanding of illness and disease on these categorizations or universals, and although in this sense research has developed knowledge of great benefit for users, that knowledge does not resonate for the single individual in her everyday living conditions and her search for 'the good' in life. It is thus difficult for individuals to recognize themselves fully in these descriptions of their assigned group.

In a meta-analysis of the view of chronic illness, Paterson (2003) outlined a model of 'the state of the art' of knowledge about chronic illness, where the condition of sufferers is understood as being on a continuum between illness and wellness (Paterson, 2003). This implies that Paterson (2003) found it difficult to frame the experience of chronic illness in a specific category. Consequently she argued for a need for differentiation in the way science understands what it means to live with chronic illnesses.

Additionally the public voice of the user organizations paints a background for this thesis by insisting that it is possible to live a good life with illness and disease. User organisations also question whether our society is health prone by imposing too great a responsibility on the individual for health and wellbeing. The moral contradictions in such communications are obvious given that people do not choose to have chronic conditions. The health science communities (Hok, Wachtler, Falkenberg, & Tishelman, 2007; Hydèn, 1997; King, et al., 2006; Mattingly, 1998a; Mendelson, 2006; Polkinghorne, 2004) from which this thesis emerges, are beginning to address issues concerning this contradiction between a traditional biomedically based universal view and an emergent view focusing on the individual. A view that allows room for diversity calls for a more distinct localising of individuals when designing and conducting research, with the aim of developing knowledge based on individual experience and is in this theses supported by hermeneutics.

Hermeneutics

Taking a hermeneutic approach is one way of addressing the call for diversity in health and social science research. Hermeneutics is both a philosophy and a methodology of interpretation. The theoretical resources for understanding narrative used in this thesis have their origins in hermeneutic traditions, as do various methods like analysis of narrative material and narrative analysis (Polkinghorne, 1995, 2004). Hermeneutics in general is about how to interpret and express someone else's expressions and is known from history of philosophy as the knowledge and ability to interpret the expressions of the gods. In social science methodology hermeneutics is used to guide the interpretation of texts, mainly by going back and forth between text and interpretation recurrently. By shifting foreground and background information, different interpretations are connected and reconnected to the interpreters' knowledge, often called their pre-understanding, in a process called 'the hermeneutic circle'. In this way an analysis expands and simultaneously opens for a transparency of the interpretations, which is valuable for a study's credibility (Denzin & Lincoln, 2005; Gadamer, 2007; Lindseth & Norberg, 2004).

The narrative analysis used in this thesis is in accordance with an epistemology taken from contemporary post-structuralist perspectives (Atkinson, 2005), based in hermeneutical traditions where interpretation is part of the understanding of social action in a temporal or real time situation. Additionally theoretical resources are brought into the analysis and interpretation, a method Giddens called 'the double hermeneutic circle' (Kaspersen, 2000). Using the double hermeneutic circle added a conscious choice of theory to the hermeneutic

procedure, which further linked and expanded the hermeneutic interpretation in a more scientific line, which also was possible to trace epistemologically. The narrative analysis used in this thesis has grown out of this tradition and procedure. It should be noted that narrative analysis can be based on different traditions such as pure phenomenology or history but these traditions will not be outlined here, as they are not part of the design (Öhlen, 2003).

Previously this thesis has approached narrative philosophically and conceptually. In the following narrative will be outlined as a methodological procedure. Narrative-based research has as varied a procedure as the understanding of narratives. Here two main procedures are traced, paradigmatic analysis of narrative material and narrative analysis (Polkinghorne, 1995). Paradigmatic analysis is conducted from narrative material like stories told of something and resulting in themes, characteristics, transformations and so on, and it is widely used in OT, OS, psychology and sociology (Polkinghorne, 1995). As shown in this thesis' general overview of conceptualisations and approaches, this kind of narrative analysis has developed valuable knowledge of patients' experiences of illness in general and of individuals' experiences of pain, suffering and therapeutic adaptation, change and transformations. Polkinghorne (1995) discusses the 'narrative quality' of this research by stating that the functions of stories told are not addressed sufficiently philosophically and epistemologically. The main body of this research, he says, is stating that storytelling is a human ability to make her special contribution to the issue at stake. Consequently paradigmatic analyses are more like traditional qualitative analyses regarding the results presented, and the narrative quality of stories told is grounded in the form of data, not in the form of analysis. Narrative analysis, however, addresses the profound individual interpretations conveyed from narrative material. Polkinghorne (1995) suggests that narrative is a human interpretative device, used by individuals to create coherence and meaning out of life experiences and circumstances. Stories are narrative material, but so are single events and all the bits and pieces that are brought together by the individual in different ways, depending on the circumstances. According to narrative theory (Ricoeur, 1984), narrative material is always situated, individually, socially, and culturally, and when being used as research material the situatedness needs to be considered in the analyses. Additionally, the narrative theory in use in this thesis states that stories as such are communicative acts (Ricoeur, 1993). Consequently the narrators direct their stories towards listeners, which means that they make an initial interpretation of the context that is asking for information, stories or events, and adjust the narrative according to their situational interpretation. Narrative material is thus grounded in the contexts from which the telling is asked for and takes place. When, for

example, respondents are asked to narrate their experience of illness to a researcher, they will supposedly do so and design a story they think will say something appropriate to the context they interpret the researcher to represent. Consequently it is important to consider the context from which data is planned to come. For example, should an interview take place in an office or in a local pub in the respondents' neighbourhood.

This does not mean that the value or credibility of the stories or the research results are questioned, but that this quality of narrative needs to be considered and addressed according to the narrative approach in use (Polkinghorne, 1995). In this thesis the design has taken these considerations into account by putting emphasis on deriving narrative material from the ongoing real life circumstances of the participants and conducted narrative analyses that accessed the interpretative quality of individual meanings.

Material and methods

I have so far tried to outline the conceptual resources and approaches which are in use in this thesis. The conceptual part of this thesis showed that the phenomenon in question, meaning in action, has a temporal quality that is impossible to grasp 'as something' but needs to be seen as 'ongoing'. Consequently this thesis is grounded in a post-structuralist approach where the phenomenon is shaped and reshaped by people engaged in activity and situated in their everyday local culture. The empirical part of this thesis then needs to explore ongoing activity, not its end result. The participants were approached as citizens, not as patients, in line with the overall research aim. Therefore the participants studied are viewed as being women living with CRC and participating in a diversified society as opposed to a biomedically labelled group deviating from the general population. Adjustments have been made regularly to keep in line with this approach, also regarding methodology. To get access to empirical data in ongoing temporal activity situations is a challenge methodologically, a challenge which in this theses is met by participant observation, where the researcher took part in the everyday activities of the women participating. This method has its origins in anthropology, where it was traditionally used to study unknown cultures over longer periods of time and resulted in analyses of culture and societal systems. Lately this method has been used to study parts of known cultures, demonstrated by Gullestad's analyses of limited social or cultural phenomenon, like 'Kitchen Table Society' (Gullestad, 1996). The chosen approach in this thesis was to explore the phenomenon of meaning-making in everyday activities of some women living with CRC by participating in the women's local culture.

Participants and sampling

Three of the women in this study were recruited from a user organization where they were members and which campaigned for social and economic justice for people with CRC. This local branch of a national organization was operating in a medium-sized town in Norway and in addition to the general aim of the organization they also formed a network and social meeting place for people in need of this kind of support. They also organized specific interest networks for groups like ‘children and parents’, the ‘the young grown-ups’ etc.

The fourth woman was recruited by word of mouth, in that one of the participants knew her and recommended her for participation in the project. See table 1 for key characteristics of the participants. The women volunteered for participation after being introduced to the project both verbally and by means of printed introductions stating the aim of the project and its ethical basis. They all signed written consent at the second meeting. All names are changed to secure anonymity. This method of recruiting was deliberate and followed the research aim of approaching women with CRC as members of a diverse population and of securing their individual agency in their realm of human everyday life.

Table 1

Study participants	Vivian, woman 31 years old	May, woman 36 years old	Lily, woman 53 years old	Esther, woman 79 years old
Time of participation the study	4 months	18 months	9 months	6 months
Medical diagnoses, duration and severity. Medication.	Rheumatoid arthritis since childhood. Needs some medication daily.	Systemic Lupus Erythematosus (SLE) since youth. Dependent on heavy medication daily. Needs frequent follow-ups by medical expertise.	Sjögren's Syndrome since youth. Dependent on heavy medication daily. Needs frequent follow-ups by medical expertise.	Fibromyalgia since middle age. Dependent on light medication daily and following a daily exercise program at home.
Everyday symptoms and general function.	Some pain and fatigue regularly. No visible body dysfunction.	Severe pain and fatigue. Limitations of body movement, especially in shoulder and hip joints. Walks with a visible 'stiffness.'	Severe pain, fatigue and eye problems regularly. Limitations of body movements, all joints. Deviations in her hands. Walks with a visible 'stiffness.'	Some pain and fatigue regularly. No visible body dysfunction.
Everyday activities and living conditions.	Student in education lives in a student apartment, together with her daughter, 5 years old. Struggles to do housework like cleaning and vacuuming. Student loan and disability support.	Farmhouse, suburban village. Married, mother of three children, 8, 11 and 17. Disability pension. Takes care of the children, does some housework. Educated in a health profession.	Family house, city suburb. Married, two grown children, grandchildren. Does some housework. Chair of the user organization in her district. Disability pension. Educated as a secretary banking.	Apartment, city suburb. Widow, three grown children and grandchildren. Participates in retirement groups connected to her church, former workplace and union. Retirement pension. Educated in the banking sector
Meaningful occupations.	Single mothering. Student at the university, graduating. Loves working part-time as a teacher. Spends time with friends and family. Looking for a new boyfriend	Loves to do handicrafts with her children, and some knitting and gardening. Engaged in user organizations for people with CRC, locally and nationally; cheers a local support group of younger couples.	Quilter, together with grown daughter. Joint engagement with husband in arts, mainly paintings. Activist in user participation, city and hospital planning. Participates in PT led exercise groups.	Writes a diary, reflects and remembers her life story. Cleans, cooks and keeps the apartment in order. Takes care of heirlooms in the home. Takes long walks. Enjoys family get-togethers.

Key characteristics of study participants.

Data collection

Participant observation was conducted over a period of 4 to 18 months through meetings with the women in their homes. The researcher participated in the women's activities of that particular day without any pre-planning either from the researcher or from the women. What happened were everyday activities, like shopping, drinking coffee, having lunch, cleaning the kitchen for Christmas, attending exercise groups, going for walks and so on. Sometimes I 'hung out' with them for 6 hours, at other times for shorter periods, but I always tried to be attentive towards the circumstances, which made me use all my knowledge of the local culture, the habits and the social factors inherent in the role of a frequent guest. All the activities were accompanied by situational conversation, pursuing initiatives coming from the participants, and I avoided initiating themes outside what was considered natural conversation in the actual situation. The material that was communicated into the ongoing participant-researcher relationship formed the data material comprising written records representing the immediate recollections and interpretations of the researcher. The initial empirical research material consisted of field notes written after the encounters, approximately 100 pages, and subsequent reflections written all through the analytical process. I did not write anything during the encounters because of the participant scope, for in my view you cannot write down observations while doing something together with someone. Then you step out of the assigned role or position (frequent guest) and might blur the situation.

Data analyses

The narrative analyses used here are based on understanding stories as a human interpretative device to link and establish causality in ongoing action and subsequent experiences. The analyses have tried to figure out how stories of meanings came into being in everyday life situations. In such circumstances activities involve shifting material and social settings, where information is managed and thoughts and conversations go on and continuous interpretation take place.

What is known as 'stream of consciousness' (James in Pollio, et al., 1997), describing experiences in practical living, is according to James always 'somebody's' stream, constantly changing, continuously dealing with objects and selecting between objects and events. James's concept 'streams of consciousness' expresses the complicated quality of the conscious being and assists this thesis in understanding the phenomenon. It was not found to be a suitable tool for eliciting and analysing ongoing everyday life. However, James grounds the individual's way of interpreting in action by his way of linking it to a specific person who

deals with objects and selects among events continuously. His way of understanding ‘the stream of consciousness’ points towards practical action as a core to detect where narrative and experience have their origins. Action is also the site where Ricoeur (1984) proposes stories to originate, by his development of Aristotle’s (1920) ideas of the threefold mimesis, described earlier, from which these narrative analyses are generated.

Analysing our empirical material, we looked for incidents and events that could be linked to possible stories. The potentiality of stories was to be grounded in the everyday activities of the women participating and linked to their local culture. Then the hermeneutic interpretation took place by first making naïve potential links between events and the researchers pre-understanding, forming initial analytic perspectives. These perspectives were repeatedly refined and reanalysed, by bringing in the conceptual approaches developed at the beginning of this project. Further foreground and background horizons (Gadamer, 2007) were shifted between the conceptual approach, the main data, the reflections and professional pre-understanding of the researchers, as described in the ‘double hermeneutic circle’ (Kaspersen, 2000). The analytic procedure thus developed over a long period of time, close to three years, forming two of the four papers of this thesis.

In summary, interpretative methodology is diverse and the approach developed in this thesis emphasises the emergence and flexibility that are provided by the chosen conceptual approaches to narratives and the subsequent narrative analyses. Thus knowledge of individual meaning-making in everyday activities in local culture was accessed in the emergent and temporal quality of everyday doing.

Research ethics

The project has followed the ethical standards of the Norwegian Research Community. Initially the Regional Committee for Medical and Health Research Ethics (REK) of mid-Norway was approached, but they did not find the project of relevance for application as no patient files were to be used. Neither were files regarding personal data like names and addresses kept. The respondents’ Christian names and phone numbers was filed apart from the data files and so was the written consent. No personal data was identifiable in the data records. Consequently the project is based on the general ethical norms and rules for data collection applicable where individuals are participating. Recommendations from the research community were followed; in that each person was initially given a verbal introduction to the project, a written overview of the research project and a written letter of informed consent to

sign. Here it was outlined that they could decide to end their participation in the project whenever they wanted without having to give any reason.

The participant observation conducted in this study brought a stranger into the rather personal and private context of the participants' homes and of the surrounding neighbourhood and social and material setting over a long period of time. This meant that the researcher got well acquainted with the women, their spouses, children and neighbours, and very specific and easily recognizable issues are omitted or blurred in the material, such as the specific place of domicile, names and gender of children, or specific stories told regarding these issues. When participant observations were about to end, the contact had to be gradually not abruptly closed. This was secured by keeping up informal contact by phone or email after the formal observation period had ended, informing participants about the subsequent progress of the research project or other issues of relevance for either the participants or the researcher.

Another ethical issue that was considered carefully all through the data collecting period was me being an OT, a profession which all the participants knew about and had sometimes consulted. The researcher did not take on this role but, if questions were asked of relevance to professional knowledge, they were of course answered, and any need for intervention was referred to the OT in the community. On the other hand this experience also turned out to be an advantage, as I was skilled and experienced in relating to people professionally and managed to position myself in the chosen position as a frequent guest all through the encounters.

Part II – Findings

Summary of papers

Paper A

Staffan Josephsson, Eric Asaba, Hans Jonsson & Sissel Alsaker (2006): Creativity and order in communication: Implications from philosophy to narrative research concerning human occupation. *Scandinavian Journal of Occupational Therapy* 2006 13:86-93.

Aims: To situate narrative as a qualitative method for exploring human occupation within a theoretical and philosophical tradition and to critically reflect on possibilities stemming from such exploration.

Material: Exploring narrative in a theoretical and philosophical tradition and examining its relation to human occupation. Further critical consideration of possible methodological implications was conducted.

Findings: In the field of OT and OS, narrative methodology was identified as used in two main ways, either as verbal data where stories are told or as narratives focused on lived occupation. In both forms of narrative research little attention is paid to the theoretical underpinnings and discourses. Further two functions of narrative are brought into focus: firstly, how narrative enables people to create order by assigning causality between experiences; secondly, to establish more existential meaning processes. The order-creating function shows how people interpret their occupational experiences by making and telling stories, exemplified in the Model of Human Occupation by narrative slopes. The creative function is connected to the concept of distanciation, which Ricoeur identifies as the element of narrative that creates freedom and space for interpretation of the material that the narrative is about.

Drawing on these two narrative theories, this paper argues that in everyday occupation these two narrative functions interplay and communicate, providing people with opportunities to establish temporal order in their interpretation but also to challenge this order and negotiate new or altered interpretations. Two examples of research using these two narrative functions are given, first creating stories from verbal accounts and then creating possible stories from action.

Conclusions: Reflections following from this outline point towards consequences for narrative research; first that narrative data are situated in the context in which they are

gathered, providing a story of a temporal interpretation, communicated by the narrator to the researcher at that moment in time and under those circumstances. This function of narrative makes it difficult to identify stable features in people's experiences. We therefore stress the necessity of situating a study based on narrative methodology in the landscape of narrative theory.

Paper B

Sissel Alsaker, Rob Bongaardt & Staffan Josephsson (2009): Studying narrative-in-action in women with chronic rheumatic conditions. *Qualitative Health Research*, 19(8),1154-1161.

Aim: To sculpt a methodology to study the 'how' of meaning-making in the everyday lives of persons living with CRC.

Material: Based on the knowledge developed in paper A and critical explorations of methodological implications, an 'enacted-narrative' approach is developed and discussed by providing material from an ethnographically based study of the everyday activities of women living with CRC.

Findings: Two views of CRC are presented, first a traditional biomedical view, which shows what people with CRC experience as losses and functional decline, concluding with needs to transform or change to accommodate to their illnesses. They are labelled as 'patients', which establishes a deviance from a normal, healthy population. This view is the basis of a huge amount of research, showing results pertaining 'what' and expressed by these and categories. Another view shows that individuals have opportunities to act and negotiate their way of forming their everyday life regardless of illness or disease. There is a lack of knowledge regarding how everyday life takes place on the basis of this view, and this paper answers a call for alternative epistemologies addressing the 'how' of everyday meaning-making.

Theoretically this paper is based on an emergent view on meaning as enacted in everyday activities rather than on meaning as an end result. This understanding of meaning is based on narrative as a human potential for interpreting and understanding their activities and experiences by putting together and telling emplotted stories in which meaning are inherent. Additionally the concept of narrative-in-action is developed, based in Ricoeur's work on threefold mimesis, in which action is linked to meanings. These theoretical resources, the paper argues, have to guide the research process and constrain the choice of method. Interview-based qualitative methods do not give access to ongoing action in an everyday context.

To get access to real time action in a particular local culture, the paper argue for using methods from anthropology, allowing for participation, co-action, observation, description, and interpretation. Due to the ‘in the moment’ quality of such data collection, it is argued for the need to prepare carefully by thinking through the position and the responses the researcher brings into the field situation. Two examples from an ongoing study using the proposed methodology are provided.

Conclusions: The paper argues that the scientific community needs to clarify its research methodology, in that the chosen view needs to be considered when methods are designed. Also of importance is that women living with CRC need to be addressed through research based on an emergent view of their situation, a view that focuses on meaning, not as a closed end result but as ongoing processes in everyday activities. Shown in the examples given, collecting data based on the emergent view of CRC shows how the women utilize interpretative possibilities in everyday action where meaning is grounded.

Paper C

Sissel Alsaker, Staffan Josephsson (2009): Occupation and meaning: Narrative in everyday activities of women with chronic rheumatic conditions (Accepted for publication in OTJR: Occupation, Participation and Health in an edited version).

Aim: To explore how women with CRC relate to meaning in their everyday activities.

Material: Ethnography, where participant observation in everyday activities of four women with CRC was conducted over extended periods. Using a hermeneutic approach to analysis, narrative analyses were conducted showing findings of enacted stories. Through the hermeneutic procedure, empirical material in the form of field notes and reflective notes were linked with theoretical resources of narrative-in-action.

Findings: The findings show how processes of meaning are closely linked to action and how the participants enacted possible meaning-related stories in their everyday lives. When enacting meaning, the women showed ambiguity by linking together events in ways that varied according to the situation. Thus the enacted processes of meaning were not goal-directed or clear but rather complex processes embedded in the women’s network of activities taking place in their local everyday culture. Sometimes they enacted meaning as part of a complete, coherent story; at other times meaning appeared as fragments with unclear connections. The analyses showed that the participants constantly questioned whether and

how they were different from the rest of the population, but also stressed the importance of being treated like everyone else. A longing to be and act like everyone else was central in the material and is expressed in the findings as enacted ordinariness. Several examples of the narrative analyses are given, showing processes of narrative in action such as ‘enacting ordinariness of mothering by uniqueness in activities’, ‘enacting the ordinariness of womanhood with an additional partner’ and ‘enacting the ordinariness of CRC in the sanctuary of *disease girlfriends*’.

Conclusions: The results are of relevance for social sciences and especially for occupational science and occupational therapy because the women’s everyday activities functioned as interpretative spaces providing opportunities for ‘trying out’ significant issues of meaning and thus worked as a way for the women to relate to and communicate with their social and material worlds.

Paper D

Sissel Alsaker, Staffan Josephsson (2009): Stories stirring the quest of the ‘good’: Narratives of women living with chronic rheumatic conditions (Submitted).

Aim: To discover how moral issues are communicated in the everyday activities of four women living with CRC.

Material: Ethnography, where participant observations of everyday activities of four women having CRC were conducted over extended periods. Using a hermeneutical approach to analyses, narrative analyses were conducted to clarify events that communicated moral issues. Through the hermeneutical procedure, empirical material in the form of field notes and reflective notes were linked with theoretical resources of narrative in action to form condensed stories.

Findings: Four stories are presented, showing how moral issues are communicated in the everyday activities of women with CRC and followed by a discussion of possible moral plots. The moral plots found are all connected to our society’s division between the moral good that is reflected in a population as a whole though not in individuals diverging from the norm. The women being labelled CRC by biomedical traditions are found to experience being different from the general run of the population they belong to due to this labelling. The way the women enact meaning in their everyday activities show how they question this possible difference, something that is condensed in their emplotted stories.

Thus each story presents different plots, regarding how and what is the good and right thing to do and be in each women's local culture. First 'A train widow' which questions 'Am I doing well enough?', where the biomedical authorities are present in the way she lives her everyday life, and she must do as the doctors tell her to do.

In the second story the plot is connected to advocacy, where the women spend lot of time and energy arguing for the need for her group to live an ordinary everyday life and to be seen as individuals who happen to have CRC. Her story 'Employed by CRC' is questioning 'What is the 'good' in my society?' This she enacts by confronting the biomedical experts, while at the same time questioning whether her work is good for her as an individual person. The third story concerns 'A planned collapse' and questions 'Doesn't engagement do good?' where the woman in the story denies the advice of biomedical authorities and does what she is engaged in even if it means excessive fatigue and a worsening of her symptoms.

The last story is called 'Jumping the fences' and proposes that 'I am like everyone else – ordinary', showing how the moral in this younger woman's story are not primarily related to her labelling but more to her generation of young students. She takes it for granted that she can do and be like everyone else, even if she needs to take some precautions regarding her condition. However her condition is not a prominent part of her story.

Conclusions: The results show how the women's everyday activities are emplotted with morality. However, the condensed stories show that the women are enacting moral quests more than issues. Their stories communicate a longing to be approached as ordinary individuals in all areas of their everyday life, also when in need of biomedical expertise. The findings thus challenge the labelling tradition in our society by showing stories of how individuals experience participating in a society where they are considered to be different.

Overall findings

From the perspective of OT and OS, the available knowledge base on meaning in everyday action is limited. This thesis contributes to the field with theoretical as well as empirical research. The theoretical papers in this thesis (A and B) explored narratives conceptually and methodologically in relation to everyday ongoing action. The concept of narrative was traced theoretically, and Ricoeur's contribution (Ricoeur, 1984, 1991) was considered in more depth regarding how narrative can be linked methodologically to human occupation.

When addressing human occupation, narrative research is mainly text based. This implies that stories are collected verbatim by means of interview and analysed with mainstream qualitative methods. The results are themes and characteristics in relation to occupations (Paper A). As shown in paper A, some stories are extracted in the contexts in which the activities narrated happen; others are collected after the fact. In paper A it is questioned whether narrative data differ according to the context of collection and whether researchers are exploring already configured stories here called 'stories told' or stories that are not complete, called 'stories in the making'. Considering possible conceptual and methodological consequences of various narrative approaches to data collection, it is shown that there is a difference between 'stories told' and 'stories in the making' (Polkinghorne, 1995). 'Stories told' inform the listener of the narrator's understanding of the experience or the incident in question. Research based on 'stories told' is mainly interview-based and the interview situation is not where the story happened. Such data is found to produce what Polkinghorne called *analyses of narratives* and results in different types of qualitative analyses. 'Stories in the making' are collected when and where they take place, and events and incidents are not linked together into coherent stories. Such data, here called action-based data, results in *narrative analyses* that show possible interpretations of events (Polkinghorne, 1995).

The finding that narrative research is approached in various, different ways (Paper A and B), has implications for narrative research in OT and OS. Therefore there is a need to consider in more depth how to conduct research regarding meaning in everyday practice. This was done by considering if and how narrative theory can inform the way we link narrative to activity. In paper B, theoretical analysis shows that narrative can be linked to action and that narrative data consequently can be action-based. Based on Ricoeur's three folds of mimesis, (Ricoeur, 1991), forms the basis for the concept of *narrative in action*, which is developed in this thesis, and conceptualises 'stories in the making'. Ongoing action provides individuals with images of previous experiences and images of future possibilities. These images give individuals options for interpretation in ongoing action, by choosing between the images that arise when acting and subsequently link them. This linking may form complete stories or just parts of stories. Paper B presents a hermeneutic procedure that exemplifies a narrative approach to ethnography, using narrative analyses induced with narrative theory. This narrative approach shows how action plays an important part in the way individuals interpret meaning in acting situations, and how these situations can be studied empirically. It is shown

that by using ethnographic methodology it is possible to combine resources from the theory of *narrative in action* with resources from the empirical field comprising action-based data.

The findings of papers A and B paved the way for the two empirical papers C and D. These papers show how meaning in action happens in the everyday activities of four women with CRC. Everyday activities of the women in the study are saturated with meanings that centre on moral and existential issues. Rich narrative material arises from actual performance of everyday activities, in the midst of present action. In such action images of prior experiences in action were produced, as well as images of possible future actions. Present action takes place in the social and material settings that comprise the women's local culture. By participating in such settings, the women enabled themselves to communicate significant issues through everyday doing.

The conceptual and empirical narrative analyses show how the women establish links between their images, links that were provisional as well as solidified. This thesis forms the basis for understanding how actual performance of activities in everyday settings provides the women with possibilities for managing important issues. Everyday activities provide interpretative spaces that open possibilities to stir up individual meanings. The women make use of these emerging interpretative spaces in their actual performance of everyday activities, by trying out alternative ways of linking together their meanings. Meaning is thus perturbed, moved or touched, disturbed or excited. Paper C shows how the women made use of these spaces to challenge, negotiate, or adjust their meanings in their everyday activities.

The narrative function which was identified in this thesis thus extends existing knowledge of change and transformations in meaning: Actual performance and participation in everyday activities supports the women in confronting the contradictions, incongruence and suspense that they experience in their everyday lives with CRC. As doing perturbs meaning, it is of relevance to ask whether everyday doing supports the women in managing the challenge of living an everyday life with CRC. By doing they meet with and are enabled to negotiate the contradictions of their everyday living.

This thesis also shows how the participating women link together their experiences, and how significant issues emerge through their individual way of establishing these links. Important findings concern how the women encounter biomedical expertise and how they view themselves as individual women. The women strongly want to act and be perceived by others as ordinary individual citizens, which is expressed in their daily actions, identified in this thesis as *enacted ordinariness* – being and becoming 'ordinary' by doing. Due to their CRC they met regularly with biomedical expertise, and experienced being treated exclusively

as CRC patients and not as individuals. These experiences challenge their individuality and agency, and repeatedly raise questions as to whether it is possible for them to ever be and act as 'good' and ordinary women. The findings in paper C show that the women enact this contradiction in a variety of activities, like shopping, mothering, as well as in the activities that are connected to womanhood. If it is not possible to be 'ordinary', they either avoid participating in the activities or develop alternative ways of doing. Such alternatives, however, must be of value in their local culture in order to be considered as compensatory for their lack of ordinariness.

The fourth paper in this thesis presents condensed stories that show how the women communicate moral values through their everyday doing (paper D). These condensed stories imply an interpretation of how moral issues were present in the data material. The plots of the stories relate to how the women interpret society's view of them, either as a group of people labelled with CRC or as good ordinary women in the local culture of their everyday lives. The women enact inherent contradictions in the way they interpret the morals of their local culture. Are they different from the general population and the individuals they meet within their everyday activities? The findings show how the women experience this ambiguity, some clearer than others, leading to ongoing and unsolved ordinariness plots. The women seem not to be sure of the way they are perceived by their social surroundings; they feel some kind of difference between everyday social settings and the context of biomedicine. This ambiguous differentiation established by their biomedical diagnoses is something that they are found to enact in their everyday activities by emplotting their stories with moral doubts regarding whether they are good enough as people and citizens.

Up to this point, this thesis has presented findings regarding the overall aim of enhancing knowledge of the everyday life of women living with chronic rheumatic conditions. The findings provided new knowledge about how these women managed their meaning relations in their everyday activities. Existing research mainly showed if and to what degree CRC impacted on everyday life in general with regard to affected individuals and the groups experience of illness, personal identity and the ability to perform and participate in activities (Alonso, et al., 2004; Charmaz, 2002; Poole, et al., 2007; Råheim & Håland, 2006). This thesis reaches beyond this, clarifying how women with CRC relate to meaning in their everyday activity. The women's medical condition is embedded in their performance of everyday activities as well as in which they manage their subsequent meaning relations. CRC and the chronicity are thus integrated in their way of everyday living.

Part III – General discussion

The following section will consider the findings in this theses in from two angles, first in relation to research questions and secondly in relation to methodology.

Considerations related to research questions

The aim of this thesis was to explore action in real time and possible moments of narrative meanings inherent in the everyday activities of women living with Chronic Rheumatic Conditions (CRC). This thesis has developed a narrative understanding of how meaning is managed in some women's everyday activities. The managing process is shown to be fluid and embedded with challenges and contradictions for the individual woman. The instability and contradictions shown within this process, present implications for the way meaning can be understood in the everyday circumstances of women with CRC. The general discussion that follows will elaborate on issues that emerged from the findings, highlighting three of these. Firstly I will discuss if and how ongoing meaning-making in action is challenging the way meaning is understood, secondly I will consider if and how participation in everyday activities opens access to negotiations regarding moral issues. Thirdly I will discuss implications for practice regarding the communication potential of everyday activities.

Ongoing meaning-making in action – challenging the way meaning is understood?

The most powerful discovery in this thesis is the women's quest for ordinariness. They want to be and act in the same way as the majority of the population. The women do not consider their condition to be outside their individuality; still the findings show that the women experience being treated as being different, as opposed to being treated as individuals who by accident have a condition which impacts on their way of living. This finding raises questions about why a society that provides good biomedical treatment for women with CRC does not also manage to provide the women with confirmation of their individuality. The knowledge base and treatment models of the OT profession are also strongly influenced by biomedical traditions and might need to consider the relevance of these findings for their treatment models and intervention strategies regarding this group.

Meaning shows to be profoundly individual and enacted in the women's local cultures. Meaning is an ongoing process embedded in acting circumstances. This view opposes traditional views of meaning as something inherent or set, which is to be reached in a goal-like manner. There is a huge amount of research-based knowledge regarding meaning for

persons with CRC, knowledge which assesses meaning as important to pay attention to but which pursues different views of meaning. Often meaning is perceived as being more instrumental – meaning is lost, lacking or needs to be found (Steger, et al.,2006). According to such a view, meaning becomes a goal to be reached through some kind of intervention, either from the affected person or from assisting professionals. These intervention models are structured as ‘input-throughput-output-feedback’ processes. Such models imply that something lacking must be added to the system to promote system change. These models are conceptually complicated and involve a large number of constituents (Kielhofner, 2002; Townsend, 2002) difficult to pay thorough attention to in an everyday practice, such as OT. Although models like these intend to capture processes of meaning-making in everyday activities, they are often used in instrumental ways only. This might occlude or simplify the central processes of embedded and enacted meaning-making, identified in the present thesis. A powerful example stems from paper B: A wheelchair is assigned to a woman. She does not want to use the chair because it is impossible for her, as she says, ‘to be a mother in that monster’. She needs transport to accompany her children on school outings. This example shows that engaged and participating individuals manage meanings in their local circumstances. Such a view might have consequences for how meaning can be assessed. Can individual meaning be assessed or attended to by questionnaires outside the acting circumstances, as is usual in for example Canadian Occupational Performance Measure (COPM) (Townsend, 2002)?

The findings of this thesis on enacted meaning, contribute to a growing knowledge base in which social scientists try to understand humans as situated social beings. Being situated means that humans continuously are managing themselves, including their bodies, in time and space. Symbolic interactionism highlights dialogues between self as a subject and self as an object, showing that people with chronic illness establish a dialogue between themselves and their illness (Rosenfeld & Faircloth, 2004). Rosenfeld and Faircloth have argued that individuals with CRC experience action as embodied. Consequently their illness is part of their interactive dialogue and thus embodied and integrated into daily life. By contrast, biomedicine treats the illness as outside the self, by talking about restrictions in the individual’s ability to move their bodies.

When related to the findings of this thesis, Rosenfeld and Faircloth’s arguments support the location of meaning as ongoing and situated. The choice of the concepts embodiment and enactment, which were central for the research in this thesis, contributes to the conceptualisation of ongoing processes in time and space. Additionally the concept of

narrative in action developed in this thesis, establishes a theoretical foundation that has the potential to expand our understanding of the time and space dimension of enacted meaning and to clarify the fluid quality of ongoing processes in everyday action.

Narrative in action may contribute to our understanding of how transformation and change may occur through interpretation. Mimesis, as presented in this thesis, has established a connection between action and images. Action produces, images that enable the individual to establish a variety of possible links between events and incidents. These possible links are alternatives, options or possibilities that individuals may opt to process into a coherent story at the time of telling. This 'exploration' space or 'as if' condition that action enables for the individual may also expand our understanding of the process quality of meaning-making in everyday action.

Previously in this section the interpretative possibilities which action establishes were considered a prerequisite for transformation and change. How such transformative processes happen are further illuminated by the mimetic function of emergence or 'the world of as if' (Bruner, 1990). In line with such reasoning, this thesis proposes that also persons with a chronic illness need to be engaged in everyday activities and practices to enable them to manage and negotiate their meanings in the unpredictability of ongoing everyday life. In addition it must be noted that managing meanings always implies making moral judgements (Polkinghorne, 2004; Ricoeur, 1984), and situated action encounters the local culture's moral, moral that individuals constantly deal with when enacting. The next section will discuss this further.

Morals embedded in local culture – do everyday activities open access to negotiations?

The quest for ordinariness that is voiced by the women in this study shows that they judge their actions in relation to some general idea of ordinariness. The women assign moral value to ordinariness as they think it represents the right and the good way of being and acting in their local culture. However, the findings show that, due to their CRC condition they are not sure if they belong to the ordinary population. This creates possible moral contradictions, which the women manage in a variety of ways. Paper D shows that contradictions are embedded in action, and illustrates how the women draw from the morality in their local culture when they act. A local culture's idea of 'the good' forms a background horizon (Gadamer, 2007) against which all individuals relate and judge within everyday action. The women are also concerned with how they are 'labelled' when they make their moral

judgements – a concern, I argue, that makes their interpretative work more challenging. Our society's tradition of labelling with respect to biomedical diagnoses is well-established and persistent due to its societal functionality. Diagnoses organise and legitimize different kinds of biomedical treatment and welfare support systems. However, this thesis shows that it is very difficult to stop the labelling from having impact on persons individuality. The women in this thesis do not get rid of the labels but find individual ways of managing them. In their everyday activities the women with CRC 'balance on the edge of their local culture', by constantly incorporating their interpretations and judgements of the 'good' into their individual activities. This is exemplified in paper D by different quests, as for instance 'Am I doing well, well enough?' or 'Isn't it good to be engaged?' The findings in paper D suggests that moral considerations are embedded in all social action for women with CRC. The quest for ordinariness is profound as societal labelling challenge individuals' interpretation of belonging inside their local culture. Differentiation thus imposes possible moral contradictions on individuals, which calls for attention by our society. The women in this research each have managed these moral issues each and every day in their own way, which raises the questions if it is possible to manage moral issues 'outside' an everyday culture. On the basis of the findings in this thesis I do not think so. I contend that it is a necessity for these women to enact, to get access to a relational understanding of themselves, of other individuals and of the local culture. From enactment emerges variation, movement, the chance to adjust, to perturb, stir up, and to negotiate the horizons of local culture. Engaging in the interpretative spaces that are inherent in action, the individual is enabled to shape the morality of their everyday environment. Promoting a person's participation in activities and in society is a highly valued goal in health and social professions (Law, 2002). This thesis contributes with a more in-depth understanding of how it is both challenging and rewarding for individuals in their everyday doings to engage in shaping-by-acting the ongoing interpretations of contemporary moral 'goods' in local cultures.

In this thesis I have argued that meaning is put into motion by enactment (paper C) and this emphasises a view of individuals as social actors who need to relate to a social and material world regardless of labels. The perspectives from women with CRC illustrates the 'fluid' quality of meaning-making as some activities were considered to lie outside everyday living, as is the case with the 'sanctuary of the disease girl friends' (paper C). Here a group of women met regularly, recognising and valuing themselves as belonging to a group diverging from the major population, sharing experiences about their bodies, symptoms, treatments and

everyday activities. However, this took place just a couple of hours each week, the rest of the time they were acting outside this sanctuary in their local culture.

I contend that it is a great challenge for individuals to continuously negotiate their moral worthiness in everyday activities. In a way this quest for ordinariness is the backdrop of societal participation for everyone in the society, but showing how it works for these women may contribute in challenging the labelling tradition. It may also influence research and professional practice to question the inherent morality in labelling which permeates individuals' everyday activities and impacts the way they judge themselves as individuals and citizens.

The communicating possibilities of everyday activities – implications for practice?

Performing activities produces interaction between individual practices and cultural practices, which, I propose, express emerging communicative processes. For OS this knowledge contributes to the ongoing exploration of the concept of occupation/activity by extending the existing knowledge regarding the temporal quality of activities. Hocking (2000) calls for additional knowledge of occupational processes unfolding through time. This thesis answers that call. Additionally this thesis provides new knowledge relevant for OS as it clarifies how meaning-making and activities are related. Narrative ongoing interpretative processes contribute, I argue, to improve the scientific understanding of how activities may facilitate change and transformation.

For OT this thesis primarily contributes to existing basic knowledge of the temporal quality of activities and their relatedness to narrative and meaning. The profession has a limited conceptualisation of ongoing everyday activities/occupations, which impedes both research and communication with other disciplines and professions. Hopefully this thesis underscores need to clarify ongoing processes of everyday action. Additionally, the empirical findings may contribute to OT's appreciation of the value of doing mundane activities in real life circumstances, by grounding assessment and interventions in concrete situations.

Considerations related to methodology

Methods

Phenomena from the realm of everyday human life are extensively researched in health and social sciences. The methodology is diverse, but qualitative methods collecting interview data are often used. In this thesis it is opted for an approach that derives from ethnography because of its closeness to real life situations involved in meaning-making. As the project is anchored in OS and OT, which are rather new research areas, I found it necessary to explore existing traditions and concepts of narrative, everyday activity, and meaning in relation to everyday human activity. The theoretical and empirical resources in use are presented in detail which strengthens transparency and credibility in all phases of the research process.

Epistemologically, the ethnographic way of generating knowledge questions the trustworthiness of the study by its interpretative mode. Participatory research touches the participants' ongoing individual matters. Actual inter-actions and communication are dependent on the attendants' abilities to interpret actions as well as subsequent talk. The presented findings can be seen as a trace of an ongoing interpretative process. Basing myself on Ricoeur's mimesis concept, I do not consider the findings to represent some kind of absolute, objective truth about the women's meaning making processes. Although such 'truth' is not an option, the data collected in the acting circumstances of the participants and the ensuing analysis may inform researchers and professionals alike, simply because it mirrors the way people make-meaning in their daily lives. Interpretation is central in most qualitative research as it is in real life when people relate and communicate, when therapists assess their clients' needs and abilities, and from which most interventions are based. Developing knowledge that trace interpretation based in both theoretical resources and empirical material I think adds valuable knowledge of contextualised ongoing communication, informing the work of both practitioners and researchers.

Ethics

This thesis has presented knowledge of how individuals relate to meanings in their everyday lives. This knowledge shows how individuals experience a strong contradiction regarding the labelling tradition in biomedicine. However I will stress that I do not oppose biomedical knowledge, nor do the participants in this study. Biomedicine has provided individuals with CRC with scientifically based knowledge and treatment that has impacted on their opportunities for living an everyday life with fewer bodily symptoms, less pain and better body functions. However, biomedicine has been given a strong authoritative power in

our society, a power that this thesis has shown to stretch outside the contexts where its knowledge base is located. I hope that the findings of this thesis will contribute to a more nuanced view of the knowledge base available for society when allocating the resources to enable individuals to live an everyday life with CRC.

Conclusions

In conclusion, this thesis has contributed to the overall aim of improving knowledge of the everyday life of women living with chronic rheumatic conditions, with an emphasis on how they relate to narrative meanings in their everyday activities in the following ways:

It has established the conceptual framework of narrative in action and subsequent methodology to study the phenomenon in question.

It has shown how everyday action provides interpretative possibilities that enable the participants to manage, adjust, and negotiate their meanings.

It has established the concept of enacted ordinariness and shown how morality is embedded in and managed in everyday action.

It has shown how society's labelling tradition impacts on everyday living and how this differentiation makes individuals question their moral worth.

It has shown the value of participation in everyday activities in local cultures, but also the contradictions that are inherent.

It has shown how processes of meaning come about in everyday action where individuals do not set their condition apart from themselves and their way of living.

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Paper A-D

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PAPER B

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PAPER C

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PAPER D

Stories stirring the quest of the good: Narratives of women living with chronic rheumatic conditions (submitted)

Sissel Alsaker and Staffan Josephsson

Introduction

Is there a moral obligation to manage well and do 'good' when living with chronic rheumatic conditions (CRC)? If so, how do women living with CRC relate to moral issues embedded in the communities in which they live their everyday life?

Morality, the difference between right and wrong, is linked to all aspects of health and social life, and embedded in society's general view of the 'good'. The 'good' denotes a culture's present and ongoing rules and beliefs regarding what it is considered good and right to do and be (Mattingly, 1998b; Polkinghorne, 2004).

Social science literature regarding CRC and moral issues addresses how clients relate to independence and autonomy (Yoshida & Stephens, 2004), how they manage and create order in their lives (Kralik, 2002; D. Kralik, Koch, Price, & Howard, 2004) and how they mediate between life event and state of health (Ville & Khlal, 2007). Also addressed is how individuals with CRC experience the 'meaning' of illness (Thorne, 1999; Thorne, Paterson, & Russell, 2003). Additionally persons living with chronic illness are said to view themselves and their experiences on a continuum between wellness and illness (Paterson, 2003), denoting that the state of the individual's experiences of chronicity varies from an everyday perspective. Individuals with chronic conditions also construct their moral selves through narratives by assigning significance to their stories (Rosenfeld & Faircloth, 2004; Yang, et al., 2007).

The biomedical aspects of CRC, implying the diagnosis and the symptoms and functional limitations of the conditions, have consequences reaching into everyday life (Kvien, 2004; Sangha, 2000). Owing to the biomedical aspects it may be difficult for the individual to participate in everyday life in the same way or with the same amount of time and energy as the general population. This also affects individuals' overall participation; people with CRC may, for example, have difficulties staying in the workforce or other of society's institutions. Addressing the consequences of CRC in everyday life, specifically the activities (Hasselkus, 2006; Law, 2002; Steultjens, et al., 2002), health professions like occupational therapy need to consider how individuals with CRC relate to morality in their everyday living, including meaning, values and engagement in occupations (Kielhofner, 2008). The literature from fields

like occupational science (OS) and occupational therapy (OT) underlines the importance of considering moral issues in the understanding and assessment of the needs of clients with CRC and assisting them in living an everyday life with chronic diseases (Alsaker & Josephsson, 2004; Clark, 1993; Fisher, et al., 2007; Goodacre, 2006; Keponen & Kielhofner, 2006).

Huibers, Marcus and Wessely (2006) address CRC from a biomedical labelling tradition, and say that diagnoses provide both pros and cons for the clients. Labelling means being judged by medical experts to belong to a group with specific characteristics, for example, pathology, symptoms and functional limitations. They argue that a precise diagnosis provides for good medical treatment and support from health and social service, as well as legitimising the implications and consequences experienced by the individual person in relation to society. There are reasons to question, however, whether diagnoses enable or disable the individual in her everyday living (Huibers, Marcus, & Wessely, 2006). Townsend, Wyke and Hunt (2006) show that individuals with conditions like CRC experience tensions between special needs regarding medical treatment and functional abilities but on the other hand they experience expectations of having to put in more effort to conform to the general level of the 'good' (Townsend, Wyke, & Hunt, 2006).

The above illustrates the complexities regarding 'the good' for particular individuals living with CRC, questions which are not thoroughly answered in the existing literature, and thereby call for additional research.

Is it possible to live an everyday life with CRC and thus live up to and conform to society's notion of the 'good'? In an everyday approach considering the experiences and activities of people with CRC, we have identified a call for ordinariness, and an urge to be able to participate in society in ways that appraise their contribution and confirm their belonging to a varied population (Alsaker & Josephsson, 2008). This 'normative quest' expresses hopes and longing among these persons to be and act like everyone else.

Biomedicine, however, needs to differentiate people from the norm by establishing diagnostic groups, a procedure fully accepted by society. Thus both persons living with CRC and society (the research community included?) take it for granted that with chronic conditions you cannot blend into the general norms as they function in today's society. Consequently, from a biomedical approach, there is something different about groups living with CRC. The individual person is confronted with and in need of the knowledge from both biomedicine and from their experiences of everyday life, and subsequently they are literally living in a contradiction. How such everyday life happens in everyday activities needs to be explored

empirically and thus the challenge to the present study was the question, **how do some women living with CRC relate to and communicate moral issues in their everyday activities?**

Before proceeding we will elaborate on our conceptual base for the notion of the 'good' and the 'normal' which are used in this paper.

Universals and particulars

Rosenfeld & Faircloth (2004) have argued that our Western society is based on a kind of generalised normality in all aspects of everyday life which is marked by fluidity. This means that people living in a local culture have inherent knowledge of what 'normal' means and how it works in their everyday life. Owing, however, to the fluid quality of normality it may change at any moment in time.

Mattingly (1998a) identified the 'good' as what constitutes moral and practically appropriate action given the exigencies of a particular situation. This means relating to and being in ongoing communication with a local culture, meaning geographical, social and material circumstances that individuals meet with in their everyday life (Gubrium & Holstein, 1997). Further, the 'good' is constantly adjusted by people acting in local cultures over time (Polkinghorne, 2004; Stern, 2004).

Our use of the notion of the 'good' in this research is grounded in Aristotle's understanding of practical action and practical reasoning, as outlined by Mattingly (Mattingly, 1998a, 1998b). When in practical action, a moral 'good' is always in question, as it is embedded in action, not divided from it. Aristotle further points out that to understand the general moral truths in a society, the 'universals', it is not enough to relate to the 'good', as one also needs to consider the particulars. Mattingly (1998b) further outlines that particulars are always concerned with action. This implies that the individual meets with and negotiates her relations with the universals of a society by her practical action. When acting, individuals practise their interpretation of the universals. In this way universals are interpreted and become embedded in particulars through actions (Polkinghorne, 2004).

Additionally, in the small moments of doing (Stern, 2004), the individual person establishes images and relations based on her knowledge of and experiences from previous actions in similar circumstances. Thus, when acting, she establishes links between herself and her prior experiences and her ideas and wishes for a future, a process identified as narrative (Mattingly, 1998a; Ricoeur, 1984).

Mattingly bases her understanding of narratives on Ricoeur's conceptualisation, using the concept of narrative in a rather ordinary but restricted sense (Mattingly, 1998a; Ricoeur, 1984). She identifies narrative as a discourse featuring human adventure and suffering, a discourse which connects motives, acts and consequences into causal chains. Further, Mattingly expresses this discourse as a process fundamental to story construction (Mattingly, 1998a, 2006). This story-making discourse also allows the narrator to understand personal meanings and experiences in the light of broader social and political contexts, and even to use such experiences to understand and critique such contexts. In other words, when activities are done in a social setting, a communication is established between universals and particulars, between the individual 'good' and society's 'good'. Narratives like this also include processes of exploring and negotiating visions of the future 'good' (Mattingly, 1998b), by linking to the past through the present and into a possible future. Stories often point towards the morally appropriate by recounting instances of moral violations or ambiguity (Mattingly, 1998b; Good & Good, 1994 in Mattingly, 1998a). In an everyday setting, stories are not complete with a beginning, middle and end and a clear plot. They are narratives in the making, and are presented as events and happenings partly linked or not linked at all, but embedded in individuals' practical action in specific circumstances.

Mattingly (Mattingly, 1998a, 1998b) argues that biomedicine offers a language, a mode of perception and an organisation of practice that denies narrative its moral status. Thus biomedicine sidesteps the moral dilemmas its clients experience, dilemmas which consequently need to be studied outside a biomedical frame. Narrative theory and analysis offer such an approach (Alsaker, Bongaardt, & Josephsson, 2008; Mattingly, 1998b, 2006; Polkinghorne, 1995; Ricoeur, 1984, 1991).

Narrative is communicated by people listening and interpreting the issues at stake, and a mutual understanding or contradiction occurs (Ricoeur, 1991). Consequently, in everyday action the individual establishes causal links in the form of possible stories, stories that convey meanings in that moment of time, meanings that may be communicated, in that they are expressed to persons participating in the acting situations (Alsaker & Josephsson, 2008). In this way, individuals relate to society's 'good' through their practical actions and receive feedback from society in return which they interpret and add to their existing narratives. This discourse or communication is central in individual lives, showing how everyday action connects to moral questions, challenges and dilemmas, establishing narrative meaning-making processes. Such narratives are highly discursive and communicative (Josephsson, Asaba,

Jonsson, & Alsaker, 2006) and accessible through narrative methodology (Alsaker, et al., 2008; Hammersley & Atkinson, 2007; Hastrup, 2003).

There is, however, limited knowledge of how this communication works for women living with CRC, something this study addresses by studying their everyday action and inherent moral issues from a narrative perspective.

Methods

This study uses an ethnographic approach like that of Hastrup (2003) and Hammersley and Atkinson (2007). Extensive field studies were conducted, where participant observations took place in everyday activities with the participants, four women living with CRC. Three women were recruited from a local user organisation, the fourth by snowball sampling, in which one participant identified another and recommended her participation. They all volunteered for participation in this study (see Table one for a presentation of the participants and their key characteristics). The study is part of a larger ethnographic project which addresses how four women live their everyday life with CRC. Our findings of how the women related to meaning in their everyday activities are published elsewhere (Alsaker & Josephsson, 2008).

The participant observations took place in the women's homes and surrounding areas over a long period of time, lasting from three to eighteen months. Each encounter lasted three to five hours and consisted of everyday activities inherent in the individual women's everyday life at that particular time.

The research material consisted of field notes written after the encounters and written reflections made recurrently through the analytic period. The research material was read and reread over this period, and analytic propositions made recurrently, from the initial naïve analyses to the more comprehensible analyses presented in the results section.

Table 1.

Study participants	Vivian, woman 31 years old	May, woman 36 years old	Lily, woman 53 years old	Esther, woman 79 years old
Time of participation in the study	4 months	18 months	9 months	6 months
Medical diagnoses, duration and severity Medication	Rheumatoid arthritis since childhood. Needs some medication daily.	Systemic Lupus Erythematosus (SLE) since youth. Dependent on heavy medication daily. Needs frequent follow-ups by medical experts.	Sjögren's Syndrome since youth. Dependent on heavy medication daily. Needs frequent follow-ups by medical experts.	Fibromyalgia since middle age. Dependent on light medication daily and following a daily exercise programme at home.
Everyday symptoms and general function	Some pain and fatigue regularly. No visible bodily dysfunction.	Severe pain and fatigue. Limitations of bodily movement, especially in shoulder and hip joints. Walks with a visible 'stiffness.'	Severe pain, fatigue and eye problems regularly. Limitations of bodily movements, all joints. Deviations in hands. Walks with a visible 'stiffness.'	Some pain and fatigue regularly. No visible bodily dysfunction.
Everyday activities and living conditions	Student in education lives in a student apartment, together with her daughter, 5 years old. Struggles to do housework like cleaning and vacuuming. Student loan and disability support.	Farmhouse, suburban village. Married, mother of three children, 8, 11 and 17. Disability pension. Takes care of the children, does some housework. Educated in a health profession.	Family house, city suburb. Married, two grown children, grandchildren. Does some housework. Chair of the user organisation in her district. Disability pension. Educated as a secretary in banking.	Apartment, city suburb. Widow, three grown children and grandchildren. Participates in retirement groups connected to her church, former workplace and union. Retirement pension. Educated in the banking sector.
Meaningful occupations	Single mother. Student at the university, graduating. Loves working part-time as a teacher. Spends time with friends and family. Looking for a new boyfriend.	Loves to do handicrafts with her children, and some knitting and gardening. Engaged in user organisations for people with CRC, locally and nationally; cheers a local support group of younger couples.	Quilter, together with grown daughter. Joint engagement with husband in arts, mainly paintings. Activist in user participation, city and hospital planning. Participates in PT-led exercise groups.	Writes a diary, reflects and remembers her life story. Cleans, cooks and keeps the apartment in order. Takes care of heirlooms in the home. Takes long walks. Enjoys family get-togethers.

Key characteristics of participants.

Narrative analyses

The narrative analyses used are based on Mattingly's (1998a) and Polkinghorne's (1995) writings, and these authors consider narrative analyses to be a hermeneutic task; trying to grasp the interplay between the actions, the social context, and the interpretation of what it is that is 'said' or communicated. Here parts (events) and wholes (happenings) from the research material were identified and re-interpreted several times until the researchers reached a consistent interpretation conveying stories concerning significant moral issues of the women (emergent plots) (Lindseth & Norberg, 2004; Mattingly, 2006; Nygren, Norberg, & Lundman, 2007; Polkinghorne, 1995; Ricoeur, 1984, 1991; Öhlen, 2003). The analyses and interpretation were based on Ricoeur's philosophy of the process of mimesis as outlined in Alsaker and Josephsson (2008) connecting narrative to action. The mimetic process has three folds, action – configuring – communicating, where the stories presented in the finding sections represent the third fold of the mimetic process. The presented stories are the researchers' interpretation of how the women communicated moral issues through their everyday activities. The first author was the participating researcher and the second author took part in the analyses.

Sharing everyday activities over time evoked numerous talks and discussions between the attending researcher and the participants, and the findings which are presented in the following show a condensation of four emplotted 'moral quest' stories (Mattingly, 2006; Polkinghorne, 1995; Öhlen, 2003).

Findings and discussion

In the following, the findings of our narrative analyses of how Esther, Lily, May and Vivian, all living with CRC, relate to and communicate moral issues in their everyday activities are presented. Our narrative analysis evoked four stories which are presented below. Each story is followed by a discussion of possible moral issues raised by the analyses.

The story of ...

'A train widow' questioning 'Am I doing good enough?'

Esther, now 79, had lived with fibromyalgia for close on 30 years. 'When I was diagnosed my physician told me I turned out positive on all thirteen points from his diagnostic scheme,' she said. 'He wanted me to stop working, I worked as a clerk in a bank, but I endured it for a long time, even when the bank entered the computing area and the screen work made my working days extra exhausting', she said, when we were having a coffee break

together in her sitting room. Esther and I met regularly in her home and talked on the telephone for about half a year. At every encounter she told me, 'there are no changes to my life or my condition'. She told of how she kept her situation stable and controlled her condition with six 'Paracet' per day and 20 minutes on her exercise bicycle, exercises in a sling attached to the roof, together with regular outside walks. Her everyday life was routine with crossword puzzles, reading, cooking and keeping her apartment in impeccable order. 'You know, I have the best of equipment, both a Kirby and a Mièlè¹ vacuum cleaner, and my children assist me when there is a need to air the carpets", she said. When I complimented her on all her wall decorations she told me that she had had a passion for embroidery and enjoyed displaying them in her sitting room, a room which she had kept unchanged since her husband died.

'And additionally I am remembering,' she added, 'I read in my diaries and remember'. She said she had been writing her diaries for 25 years, still did a couple of sentences every day. 'I remember most of it, but need to catch up with time and dates', she said. 'Every day after dinner I sit down in my armchair and reflect and rest, I need a lot of rest', she said, adding with a smile 'but I know the "art of living with" after all these years'..

Another day, when we prepared the coffee table together she told me she was going to town the next day at noon to meet with what she called 'the railroad wives' club'. 'We meet at a downtown pub once a month, all of us have been married to engine drivers, and we are just thirteen left now, as several have passed away. We talk about how life was when our spouses were alive' she said. Mentioning her husband, her eyes went blank, but she continued 'the day he died was my worst ever, I still think March is a heavy month to live through', she said, 'he passed away on the tenth, just died at work, I did not reach him....will never forget...' she said. 'We had a wonderful partnership with no conflicts, and I miss him more every day'. She had previously told me that she had been a widow for more than 30 years.

On my first visit to her home I realised that every now and then a train passed just outside, and made a recognisable noise, and when I asked Esther if she was disturbed by it she answered, 'I do not hear the train, I have always lived by the railway, my father worked there, the railway has always been close'. Esther also said that she greatly enjoyed to read travel books and atlases, and that she travelled to 'Syden' once a year with the CRC consumers' travel agency, staying at a rehab centre, 'but just for two weeks' she said, 'that's enough'. On this year's trip she had had some bad experiences: 'You know the physiotherapy (PT)

¹ Kirby and Mièlè are expensive vacuum cleaners of high quality, but with slightly different functions.

treatment is usually good for my condition, but this time the treatment hurt and I told the PT that it was not good for me, but he put a considerable pressure on me to endure the pain even when I told him that my physician has said that I am not to do exercises that pass my pain limit. And additionally the whole group with which I was travelling had to handle the luggage on our own, owing to new security regulations in airports, so I think this was my last trip', she said.

Esther lived on the second floor of a two-storey house which the couple had bought when they moved to this town some 60 years ago. She had grown-up children, two of whom lived in separate flats on the first floor and Esther made them dinner every day. The third child had a family and lived in another part of the country. They all spent time together at Christmas and other occasions, and Esther described their last family gathering as follows: ' We had sooo much fun all Christmas...' and when I asked what they were doing, she said 'just being together'.

We have identified the plot of this story to be the contradictions between Esther's chosen authorities and her ongoing everyday experiences. She worked hard to do what the doctors told her to do, keeping up a stable everyday life, balancing between exercise and rest, taking the prescribed medication and keeping up her everyday routines according to their recommendations. She seemed to regulate her everyday activities so that she prioritised following the doctors' advice, and then attended to her own wishes and interests. In our understanding she has given biomedicine authoritative power in her everyday life at home, not just regarding her condition. Following Huibers and colleagues' (2006) reasoning as presented in the introduction this can be seen as an example of how diagnoses and treatment recommendations can disenable individuals in their everyday living. She seems to conform to the universals of biomedicine, and in our interpretation she was accepting that her condition in a way 'was herself'. She could have put her individual everyday interests first and adapted to the doctors' advice, but we found that she preferred to do it the other way.

In our interpretation of her narrative she accepted that her condition and subsequent labelling had weakened her individual autonomy. Yoshida & Stephens (2004), however, report that individuals often make their priority doing valued activities in their everyday life at the expense of managing their arthritis. For Esther, however, we argue that her actions can be seen as similar to conforming to society's 'good' (Mattingly, 1998b), that it was the right thing to do. She did not always allow herself act like a particular individual with her own moral 'good', in which her values and interests were prioritised at the same level as those of the biomedical expertise.

When her actions made her meet with events that challenged her 'story', she became frustrated and avoided such activities, like going to 'Syden' (travelling south (Syden) to a treatment centre for a couple of weeks). It is considered beneficial for CRC patients to travel to 'Syden' to get treatment in a warm climate, and she had enjoyed both the adventure of travelling and the treatment. On her latest tour she was treated by a physiotherapist (PT) who told her to change her exercises and routines. She expressed frustration and in our interpretation she avoided considering these new ideas of treatment and exercises by saying that she would not travel any more. Instead she kept up her habitual everyday activities in which her actions did not put her in connection with challenges that forced her to alter her story. The causal links that she had established and which made up her narrative she resisted changing (Mattingly, 1998a).

The analyses convey a woman belonging to a generation and social class where the moral 'good' was to work hard and to do the right things. Her interpretation of the moral 'good' in society and biomedicine was similar to her individual moral 'good', and not to be challenged without great frustration, though it may seem to limit her engagement in everyday living. One way of understanding this is that she had been living with great losses over 30 years, first husband, then health, and through her everyday activities managed to keep up her pride and independence by being what she considered a 'good' person in her situation, even if it meant sacrificing activities that she had enjoyed. She did not communicate that there were options she could try to do things differently. Negotiations did not seem of relevance to her. She was stuck in a way (Mattingly 1998b) with the plot of her story, not willing to let her 'good' be challenged.

The way we interpret her narrative, it was emplotted by keeping up stability regarding what she thought were the good and right things to do. From such a perspective, her actions were understandable, but also evoke questions as to whether her story was driven by a quest like 'Am I ever good enough?' She literally lived the contradictions inherent in a cultural narrative between the universals and the particulars, or the moral good for a group or population with CRC, in contrast with the moral good of particular individuals with CRC. She could not make links between the two approaches and was stuck. In any case, that was the way her everyday came about.

The story of ...

'Employed by CRC' questioning 'What is the 'good' in my society?'

Lily, a middle-aged woman I met with for close to two years, had lived with her disease for more than 30 years and been active in the local user organisation most of the time. She lived off disability pension but frequently taught medical and health students from her user perspective and represented her diagnosed group in a variety of municipal organisations. She said, 'I try to make the doctors understand that they need to ask what this means to you in your daily life, not just about symptoms and effects of medications' and added, 'and I tell them to ask their patients "what does it mean for you when the mundane and common activities in everyday life are difficult, like toilet hygiene, dressing and the like", they need to understand the challenge it is when body movement is so limited. CRC occupies very many hours of my life'. 'Sometimes I feel like I, Lily, disappear for the doctors, just the CRC is left for them to engage in'. And she says, 'It's interesting that other more mundane medical problems also disappear'. She then told how she had for a long time had problems with her toenails, they did not grow well and nicely and she was embarrassed to wear sandals during summer. When she eventually brought it up, it was treated in a couple of weeks, and she could use sandals. 'What do you think...It took me ten years! I never felt it was an important enough problem to bring to the doctors. You know I know almost everything about my medical diagnoses, often I am better informed about new treatments than my doctor'. Working in the local user organisation she also told how she thinks these organisations perhaps have focused too much on the medical side, but on the other hand it has been important for patients to be able to discuss their treatments with the medical experts, and to do that they need knowledge. ' But perhaps it has gone too far,' she said, 'my experience is that I am an expert on my own diagnosis and treatment but no longer an expert on me, Lily'. Lily and I discussed these issues one rainy morning in December sitting at her old marble kitchen table polishing all her copper utensils, a typical Norwegian task before Christmas, and she owned a lot of them, so we had hours of talking.... 'Did you see my notice in the paper?', she suddenly asked. She had written about the lack of rehabilitation services for her diagnosed group, pointing to how important it was for people with CRC regularly to have access to services which aimed at 'the living with' problems, not just the biomedical issues. 'You know, we have these new centres for learning and mastering, but I am so tired of hearing again and again about all the phases I have to live through, I need something concrete to do or talk about, and advice and discussions on how best to maintain my physical and social abilities in my everyday life', continuing, 'I always talk of the importance of these

issues when I represent my user organisation in different societal organisations, but I am not sure they are listening, I often have a feeling that I am there just because the law tells them to bring in persons from the user groups to be heard in service planning’.

The copper things were shining bright when her husband entered the room....

The narrative analyses of the events that are linked together in this story show how Lily experienced doing advocacy work in circumstances where knowledge of biomedicine is in focus. In a biomedical setting, the knowledge used by women with CRC is of course the universals of the condition found in the labelled group (Kvien, 2004). The particulars, experienced and lived by individuals in an everyday life setting, are not thoroughly attended to, Lily felt, though biomedical research recognises everyday life as affected by the condition (Kvien, 2004). In our interpretation, Lily implies that individuals with CRC like herself miss experiencing being treated as individuals who live diverse everyday lives. They have different interests and do different activities in which they manage the symptoms and consequences of CRC in a variety of ways. Biomedicine’s tradition of focusing solely on the diagnosis and treatment of the CRC symptoms she experiences as making it difficult to attend to other aspects of importance to individuals. Her example of not feeling comfortable voicing her problems with her toenails in the biomedical context is, in our interpretation, because she did not consider it important enough compared with her CRC.

This, we find, shows how an individual problem, though belonging in the world of biomedicine, is assigned moral worth by Lily (Mattingly, 1998a; Polkinghorne, 2004). She thinks that her problem with her toenails is too simple to bother the experts with, and considered to belong to her the everyday circumstances. Her longing to be treated as Lily, an individual person, is in our reading obvious, though she is suppressing this longing when advocating what she thinks supports the group she is labelled in. The plot of her story conveys this contradiction, but also shows that she herself is realising it, and she has made the causal link, giving the story a clear plot (Mattingly, 1998a; Ricoeur, 1984) that communicates what we understand as her longing for not having to divide aspects of her way of life according to her acting context.

Her narrative, however, is interpreted to have open endings, in that she is questioning if biomedicine eventually will listen to her advocacy of individuality. Or will she give up? Additionally, by continuing advocacy, she finds her actions make her constantly face the contradictory approaches of biomedicine and everyday life. According to narrative theory, action produces images and possibilities for future actions (Josephsson, et al., 2006; Ricoeur,

1991) and perhaps her presence and action in the biomedical context may at least stir the focus of the meetings between the biomedical knowledge of her condition and her individuality. By continuing her work, she is keeping up instability and she is creating options for negotiation and possibilities for change. Narratively she is constantly questioning the causality, the way both she and the biomedical context establish links between universals and the particulars (Huibers, et al., 2006; Josephsson, et al., 2006). By her actions she is establishing communicating options (Ricoeur, 1984), voicing particulars, hoping that the diverse group of people with CRC will also be treated as individual persons with a diagnosis that needs to be attended to, but her narrative also shows unpredictability by her voicing her image of becoming a diagnosis herself.

The story of ...

'A planned collapse' questioning 'Doesn't engagement do good?'

May is 36, married with three children and engaged in user organisations. She said, 'After they gave me my diagnosis I thought the pain would disappear, but it did not happen. Then I decided that the diagnosis was wrong and acted like that. But when I eventually met with people from the user organisation I discovered you still could have fun even with such a diagnosis'. May works both locally and nationally in a user organisation and her main aim is to change the way the organisations work; she wants to offer the members something else apart from coffee breaks, small talk and raffles. She said that the older generation had been leading the local group and it was suited for that generation. She, however, felt that there was a huge group of younger people with CRC who needed another type of arrangement. 'We in between' was one of her projects adjusted to young adult members and she had applied for and got a government grant to establish this group consisting of CRC-affected persons and their families. Meeting her just before the arrangement started I complimented her on looking good and on her outfit. She said, 'I'm on mega doses of cortisone to keep me going, have decided to follow this arrangement through, we are about to hear lectures from health persons on avoiding back pain in everyday life and some theory about relations, you know many attending here are married to a CRC person, and of course it affects the relationships, and then we are serving lots of good food and talking'. This was a whole day arrangement, continuing with a party in the evening. Then she continued, smiling, 'Tomorrow I'm going to have a collapse'. We had met regularly for nearly two years, and she had told me similar stories before, how she used all her energy in similar projects and managed to forget her symptoms while engaged, and then spent the following days in bed. 'You know it's the way I

can get things done, but I'm so sorry it's not possible to adjust to a working environment, I was so sorry I had to stop working, but the employers were not even interested in negotiating with my working capacity', and she continued, 'I then realised the advantages this could give regarding spending time with my family and work for my user organisation'.

When ending the lectures on relations, the lecturer cited a poem written by May long ago; 'My partner lupus –you want to make all the decisions – but you know we're supposed to be two in a partnership...'

This story can be seen as mediating how May has been investing energy and engagement into establishing a societal position for herself by making use of her competence which employers could not use. Her working style in which she regularly exhausted herself completely was contradictory to the general advice given from biomedicine on how to act with her condition. We interpret that she is denying doing what in biomedicine is considered the right and good way of acting with such a diagnosis. As we see her actions, she refuses to accept the biomedical story of what is good for her condition. She does what she experiences is good for her particular person, and so she is establishing another causality in her story that she considers good for her.

Another way to understand her actions is that she enabled herself to take part in decisions concerning herself, her condition and her everyday living. On the other hand, the knowledge she opposes by her way of acting has a strong authoritative power in biomedicine (Huibers et al., 2006), but she does not seem open to negotiation (Alsaker & Josephsson, 2004; Polkinghorne, 1996) as regards her way of attending to her symptoms and the biomedical advice. May seems to decide what and how she should act and she does it, ignoring the biomedical authorities, and enables an everyday life, participating in what she finds important and consistent with her moral good (Law, 2002; Mattingly, 1998b; Polkinghorne, 2004). As we understand her way of making causality in her story, she strongly valued social relations in everyday living, seeing herself as an individual but socially related. This she enacted by advocating that persons with CRC also live with partners and families, and that such relationships needed attention. By her actions she provided alternative images of how an everyday life with CRC could come about (Mattingly, 1998b), images that she communicated to other individuals with CR and their partners and families.

In her story we also found a powerful metaphor (Bruner, 1986) in her way of describing herself as 'being in a partnership consisting of me and lupus'(her diagnosis). Her expression 'I

am denying lupus to make all the decisions' we understand as conveying her images of being recognised as an authority in her everyday life, valuing her interests and abilities. Her way of acting by overworking for periods and collapsing afterwards we find challenges the good of everyday living with chronic conditions that health professions argue for. As we interpret her story, however, she herself had established links and causality that established coherence and meaning for her (Mattingly, 1998b; Polkinghorne, 2004). Additionally her actions provided her with feedback from users attending her arrangements, confirming the value she put into viewing and recognising individuals with CRC as belonging in families and social relationships. We identified that her story stirred and blurred existing general images of individuals living with CRC, by showing alternative and probably new images of chronicity, both for the attending persons and supposedly for herself. Thus her actions provided her with ongoing meaning-making opportunities in her everyday activities, possibilities that according to the theory of narrative-in-action pave the way for ongoing interpretation and negotiations of meanings (Alsaker & Josephsson, 2008), as, for example, if engagement continues to be good.

The story of ...

'Jumping the fences' questioning 'I am like everyone else – ordinary...'

Being 31 and the mother of a 5-year-old daughter, Vivian thought she was a bit old to be a student, but was about to graduate in education and very eager to start her teaching career. She lived in a small student family apartment, struggling to keep it nice. Having breakfast together with her daughter at the kitchen table, she said she had had severe rheumatoid arthritis since early childhood, but kept the symptoms under some control with daily medication. Some pain and especially fatigue marked her everyday function with unpredictability. She had needed some extra time to reach her graduation, as she could not study with the expected stability, some days she was unable to think and act and just spent the entire day on the sofa. 'Luckily I had a relative well educated in the social support system who managed to assist me in prolonging my economic student support, allowing me the necessary breaks without starving', she said. She was very eager to start working, but it was not easy to get even a part-time teaching job in this city, especially as she felt it appropriate to tell about her CRC when applying for posts, but 'I am very persistent', she said, 'so eventually I will get started teaching'. One sunny day I found her sitting outside the apartment together with a neighbour. She asked me to join them, as she did not want to stay inside today. I sat down, facing the apartment

entrance on one side and the fence of the kindergarten opposite. Both the women had their children there on a daily basis, praising the opportunity it gave them to finish their education, especially since they both had experienced the fathers of their children bailing out of the relationships during the winter. They completely agreed that those young men were unable to cope with the responsibility inherent in parenting in the long run, especially when students; the boys wanted to party and play soccer instead of babysitting and changing nappies. They both expressed great doubt about finding new partners. This gender issue discussion was interrupted when two small foreign boys arrived and started to climb the fence of the kindergarten. 'These boys envy the children inside, but they are not allowed to attend by their fathers,' they said. Not attending the kindergarten meant that the boys did not learn to speak Norwegian and were not able to play with the children in the neighbourhood. Both women then engaged in explaining to me that the boys' fathers were 'far-away-from-students' at the university, and they brought their wives with them to care for the children and be housewives. The women are never outside, they said, they just stay inside their apartments while their husbands study and their children just run wild, using whatever they find to play with, regardless of who owns it; there is no one to teach them the rules and regulations of the neighbourhood. 'Of course they should be in the kindergarten with the other children, and their mothers should have had the opportunity to learn our language and socialise with other inhabitants,' the two women students agreed passionately, 'but you know "those" men....' they added.

Our next scheduled meeting was after the summer break and Vivian called me the day before, telling me enthusiastically; 'I have got part-time work and moved to Greenriver, and my new boyfriend lives here and my daughter loves her "extra pair" of grandparents; do you want to come and visit...?'

In our interpretation, Vivian's story is of a young woman, doing, thinking and acting like her fellow students, questioning images of relevance for her, like gender issues, like being a student mother and the possibility of establishing romantic relationships. We see the event with the two foreign boys as producing images for the women that offer an opportunity to talk about these gender issues at a distance. Using Ricoeur's understanding of the concept of distanciation, it means that events like the one the women are experiencing enable them to attend to issues that are recognisable though not similar to their own experiences. This function of distanciation establishes an interpretative space where the women can try out images and contradictions of relevance to their own life and experience (Josephsson, et al.,

2006; Ricoeur, 1984). In Vivian's story we identified this distancing function of narrative that enabled her to engage in a discourse with her student friend regarding issues of relevance to women's opportunities to become educated and simultaneously to take care of children. Additionally we understand that the discussion between the two women regarding living with their children's fathers was stirred by the foreign students' children. The children seem to evoke images in the women of issues of gender and culture, like the father being a student, and the woman had to stay home and care for the children and the home. In our interpretation the two fellow students found, by experiencing the event with the small boys, an interpretative space to try out images of relevance to significant issues in their own story of being single mothers, but wanting to be employed and get new partners.

In our understanding, Vivian's condition is not prominent in her narrative, but paints a kind of background horizon (Gadamer, 2007) of the two women's everyday neighbourhood discourse. Vivian's questions of what is the good and right thing to do we understand to be recognisable for both women, as they obviously share images and significant issues of the local culture where they both live.

Additionally we interpret her story to mediate flexibility in her story-making by her way of making changes in her everyday activities when opportunities appear. Seemingly without hesitation, she moves, starts working, establishes a relationship. We identify that she is re-enacting her story as though saying, 'I can do what the ordinary young women do', and she does not add, 'even if I have CRC' (Alsaker & Josephsson, 2008). We find that she seems to take it for granted that she can make choices and act like her friends, but on the other hand she also acknowledges that she needs biomedical treatment, assistance and adaptations to do what she wants, completing her degree and caring for her child in a good way. We understand, however, that she communicates that she does not seem to put a great emphasis on that, but takes it for granted that she will get the help she needs when and where she needs it. She has literally jumped the fences of labels and norms, and acts as a young woman in her local culture.

Concluding reflections

The study aim was to explore how four women living with CRC related to and communicated moral issues in their everyday activities. Our narrative analyses showed that the women communicated events and happenings in which they linked moral quests more than issues. Moral quests identified were, for example, Esther's questioning if she was doing well enough and Lily who was wondering about her society's good. These quests we found to be not quite

consistent in that the events and happenings were not clearly linked and causality was not always established between significant events and happenings. In any case, narrative material which is embedded with meaning in this way is ripe for interpretation. Our interpretation is previously presented in the form of the four stories and the subsequent discussion.

The findings show different aspects of everyday lives with CRC, and everyday life where the women's conditions added unpredictability owing to their varying bodily functions. They also experienced another unpredictability, however, that of being good enough citizens. The way we understand the labelling tradition of our society, dividing people into groups on the basis of, for example, medical diagnoses, the women experienced it as contradictory. On the one hand they experienced great advantages from the knowledge, treatment and support available to them from the biomedical realm, by easing their symptoms and making their everyday living more secure and predictable. On the other hand they seemed in a way to assign moral value to belonging to a labelled group, by not being able to contribute to society by the same means as the general population.

In conclusion, in our interpretation the stories presented mediate moral quests, not clearly defined issues. The quest is, we find, to communicate the significance of their experiences as human beings participating in a society where they are considered to be different. The narratives show unpredictability and unsolved issues, but the instability varies for the women. In any case the way they participate in everyday activities in their local cultures opens possibilities for them to be agents, to be themselves, not their diagnoses, where acting means taking part in the communication of their local culture and by that challenging it.

Methodological considerations

The process of interpretation showed in this paper exemplifies how stories come about (Polkinghorne, 1995), how they can be interpreted and thereby provide communicative possibilities. The narrative analyses convey the researcher's interpretations, based on material from the first author engaging in the everyday activities of the participants. The activities that took place were initiated by the participants regarding what to do, and how and when to do it, and so was the case for the subsequent conversation that followed along with the doing (Alsaker, et al., 2008). The interpretation is grounded in authors' pre-understanding and long experiences as occupational therapists and teachers of OT, as well as personal experiences and academic knowledge from social sciences. Even if we tried to heighten our awareness of

this when doing the analyses, some bias may still be present in personal issues and comments. Clarifying the theory in use and our professional status is done to make the analyses more transparent and the results more credible.

Epistemologically, this way of generating knowledge questions the trustworthiness of the study by its interpretative mode. We are not trying to tell the women's true stories, however, but are tracing our interpretation of it. Additionally, we argue that interpretation is central to most qualitative research and also in real life when people relate and communicate and when therapists assess their clients' needs and abilities, on which most interventions are based. Developing knowledge that traces interpretation based on both theoretical resources and empirical material might add valuable knowledge of contextualised ongoing communication that might inform the work of both practitioners and researchers.

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