

## Stories stirring the quest of the good: narratives of women living with chronic rheumatic conditions

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This ethnography based study explored how four women living with chronic rheumatic conditions related to and communicated moral issues in their everyday activities. Narrative analyses were conducted and showed that the women linked everyday events and happenings to moral quests rather than to moral issues. The analyses are presented in the form of four stories, stories which are emplotted with different moral quests, quests that are grounded in the women's everyday doing. For example, one woman was concerned if she was doing well enough and another woman was wondering about her society's good. The four stories that form our interpretation show how the women experienced and managed unpredictability and contradictions in their everyday life and activities, due to their conditions and society's labelling traditions. The quests communicate the significance of their experiences as human beings participating in a society where they are considered to be different.

**Keywords:** narrative analyses; everyday activities; moral; chronic conditions; ethnography

### 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 view of the 'good'. In this paper 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), originating from a narrative approach to morality (see Thorne et al. 2002 for a review of different approaches on morality).

Social science literature regarding CRC and moral issues addresses how clients relate to independence and autonomy (Yoshida and Stephens 2004), how they manage and create order in their lives (Kralik 2002; Kralik et al. 2004) and how they mediate between life event and state of health (Ville and Khlal 2007). Also addressed is how individuals with CRC experience the 'meaning' of illness (Thorne 1999; Thorne, Paterson, and Russell 2003). Additionally, persons living with chronic illness

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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 and Faircloth 2004; Yang et al. 2007).

The biomedical aspects of CRC, implying the diagnosis, 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 daily life, specifically everyday activities, i.e. activities that are performed on a regular basis in everyday life (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 activities (Kielhofner 2008). The literature from fields such as 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 and Josephsson 2004; Clark 1993; Fisher et al. 2007; Goodacre 2006; Keponen and 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 legitimizing the implications and consequences experienced by the individual person in relation to society. There are reasons to question, however, whether diagnoses enable or disenable the individual in her everyday living (Huibers, Marcus, and 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 'good' in society (Townsend, Wyke, and 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 and Josephsson 2010). 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 consequently 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 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 and Faircloth (2004) have argued that our Western society is based on a kind of generalized 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 and 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 conceptualization, 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 and 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 (1998a, 1998b) argues that biomedicine offers a language, a mode of perception and an organization 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, and Josephsson 2009; 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 and Josephsson 2010).

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 et al. 2006) and accessible through narrative methodology (Alsaker, Bongaardt, and Josephsson 2009; Hammersley and 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 similar to 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. Strategic sampling was used (Kvale 1996), recruiting three women from a local user organization, and 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 1 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 and Josephsson 2010).

The participant observations took place in the women's homes and surrounding areas over a long period of time, lasting from 3 to 18 months. Each encounter lasted three to five hours and consisted of everyday activities inherent in the individual

Table 1. Key characteristics of participants.

<b>Study participants</b>	Vivian, woman, 31 years-old	May, woman, 36 years-old	Lily, woman, 53 years-old	Esther, woman, 79 years-old
<b>Time of participation in the study</b>	Four months	18 months	Nine months	Six months
<b>Medical diagnoses, duration and severity</b>	Rheumatoid arthritis since childhood.	Systemic Lupus Erythematosus (SLE) since youth.	Sjögren's Syndrome since youth.	Fibromyalgia since middle age.
<b>Medication</b>	Needs some medication daily.	Dependent on heavy medication daily. Needs frequent follow-ups by medical experts.	Dependent on heavy medication daily. Needs frequent follow-ups by medical experts.	Dependent on light medication daily and following a daily exercise programme at home.
<b>Everyday symptoms and general function</b>	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.
<b>Everyday activities and living conditions</b>	Student in education lives in a student apartment, together with her daughter, five years old. Struggles to do housework like cleaning and vacuuming. Student loan and disability support.	Farmhouse, suburban village. Married, mother of three children, eight, 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 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.

Table 1. (Continued)

Study participants	Vivian, woman, 31 years-old	May, woman, 36 years-old	Lily, woman, 53 years-old	Esther, woman, 79 years-old
<b>Meaningful occupations</b>	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 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.

women's everyday life at that particular time. In each encounter the researcher participated in whatever activities that the women initiated at that particular time, like shopping, taking part in a fitness group, meal preparation and having coffee breaks.

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.

### ***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 and Norberg 2004; Mattingly 2006; Nygren, Norberg, and Lundman 2007; Polkinghorne 1995; Ricoeur 1984, 1991; Öhlen 2003). The stories presented are results of the narrative analysis that were conducted. The analyses and interpretation were based on Ricoeur's philosophy of the process of mimesis as outlined in Alsaker and Josephsson (2010) connecting narrative to action. The mimetic process is three fold: 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). The stories presented are the results of hermeneutic narrative analyses, grounded in our analytic work with narrative theory and empirical material.

### **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.

#### **'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 Mièle<sup>1</sup> 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 13 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 10th, 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 recognizable 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) 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'.

Our understanding of Esther's narrative convey a woman belonging to a generation and social class where the moral 'good' was to work hard and to do the right things. For her, this meant that she as an individual had to conform to authorities. Consequently her interpretation of the moral 'good' in society and biomedicine was similar to her individual moral 'good', and moral 'good' do not change easily, though it may seem to limit Ester's engagement in everyday living.

We have identified the plot of this story to be the contradictions between Esther's view of 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 prioritized 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 disable 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 tried to include the doctors' advice, but we found that she preferred to do it the other way by letting the doctor's advice govern her everyday life and activities. In our interpretation of her narrative she accepted that her condition and subsequent labelling had weakened her individual autonomy. Yoshida and Stephens (2004), however, report that individuals often make their priority doing valued activities in their everyday life at the expense of managing their arthritis, like May in the example below.

For Esther, however, we argue that her actions can be seen as similar to conforming to society's 'good' (Mattingly 1998b), and that it was the right thing to do. She did not allow herself to act like a particular individual with her own moral 'good', in which her values and interests were prioritized 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. This made her not want to go to Syden anymore. She expressed frustration over her own decision and in our interpretation she avoided considering these new ideas of treatment and exercises as they challenged her 'moral good'. 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). One way of understanding this is that she had been living with great losses over 30 years, first her husband, then her 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. We understand that this also meant sacrificing activities that she had enjoyed. So sacrificing activities that she enjoyed was not a novel experience for her. Interesting, however, was that it was the PT who in her view belonged to the biomedical authority that challenged her until now established stability.

She did not communicate that there were options she could try to do things differently even if she expressed frustrations. 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?’

The above interpretation exemplifies 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. Change and exchange between individual and cultural narratives is ongoing continuously and in Esther’s case she was unable to make the required changes or adjustments necessary. She could have easily told the PT that she had developed her way of managing her condition and told how the PT could assist her in keeping up her function. But in her view of moral good there was no place for negotiation and user agency, she could keep order (Josephsson et al. 2006) by doing ‘the right thing’, though her expressed frustration could indicate that she had some doubts. In a way she seems to be stuck (Mattingly 1998b), being unable to alter the way she linked together the two approaches, and she did not get any help from the therapist. It could be asked if the therapist ought to understand her ‘moral good’ and initiate negotiations with her. In any case, that was the way her everyday life came about: stable but less enjoyable.

#### **‘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 organization most of the time. She lived off a disability pension but frequently taught medical and health students from her user perspective and represented her diagnosed group in a variety of municipal organizations. 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 10 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 organization she also told how she thinks these organizations 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 organization in different societal organizations, 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 universal 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 recognizes 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 it to belong to her 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, Marcus, and Wessely 2006; Josephsson, et al. 2006). By her actions she is establishing communication 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.

### **‘A planned collapse’ questioning ‘Doesn’t engagement do good?’**

May is 36, married with three children and engaged in user organizations. 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 organization I discovered you still could have fun even with such a diagnosis’. May works both locally and nationally in a user organization and her main aim is to change the way the organizations 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 organization’.

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, Marcus, and Wessely 2006), but she does not seem open to negotiation (Alsaker and 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 CRC 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 recognized 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 recognizing 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 and Josephsson 2010), as, for example, if engagement continues to be good.

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

Being 31 and the mother of a five-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. The concept of distanciation in Ricoeur's understanding of the concept (Josephsson et al. 2006; Ricoeur 1984) is a function of narrative that is a tool to manage and negotiate narrative plots.

Vivian's story is about being a young woman, student and single mother that has experienced being left alone with her child, but at the same time has options to care for herself and her child both socially and economically. Despite her experiences, she has hopes and wishes to find a new love, work and build a home, though it may be hard, since she needs to take some extra care of her body. When the boys enter the scene the women engage themselves in their situation, expressing very strong emotions regarding the boy's situation.

Events like this enable Vivian and her friend to attend to issues that are recognizable 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). They are able to try out their thoughts and emotions, such as *what if it had been me who had no education, no job opportunities, being dependent of a husband?* 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 in the women images 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, such as *will I manage this, can I get a job, is it possible to find new partners?* For them this was absolutely a possible future reality. Using the distancing function of narrative they communicated their past experiences, their fears and their hopes for the future, by narratively reviewing their images of the boys' circumstances. Thereby they established order in their own narrative, making causality between education and job opportunities; between joys and fears of managing being single mothers, and possibilities given them in the Norwegian welfare system. 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 recognizable 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 and Josephsson, 2010). 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, complete her degree and care 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, Esther by her frustration when her ideas of doing the right thing was challenged, Lily by questioning if her effort to inform and understand the biomedical system made her lose her individuality and May by acting according to her own interests and engagement. Vivian seemed to take it for granted that she could live an ordinary life despite her CRC, but would need adaption and support of different kinds from the welfare system. These narrative analyses show examples of how the women living their everyday life with CRC communicated their uncertainty regarding 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 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, Bongaardt, and Josephsson 2009). 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 contextualized ongoing communication that might inform the work of both practitioners and researchers.

### **Note**

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

## References

- Alsaker, S., R. Bongaardt, and S. Josephsson. 2009. Studying narrative-in-action in women with chronic rheumatic conditions. *Qualitative Health Research* 19, no. 8: 1154–61.
- Alsaker, S., and S. Josephsson. 2004. Negotiating occupational identities while living with chronic rheumatic disease. *Scandinavian Journal of Occupational Therapy* 10: 167–76.
- Alsaker, S., and S. Josephsson. 2010. Occupation and meaning: Narrative in everyday activities of women with chronic rheumatic conditions. *OTJR – Occupation, Participation and Health* 30, no. 2.
- Bruner, J. 1986. *Actual minds, possible worlds*. Cambridge, MA: Harvard University Press.
- Clark, F. 1993. Occupation embedded in a real life: Interweaving occupational science and occupational therapy. *American Journal of Occupational Therapy* 47, no. 12: 1067–78.
- Fisher, G., L. Emerson, C. Firpi, J. Ptak, J. Wonn, and G. Bartolacci. 2007. Chronic pain and occupation: An exploration of the lived experience. *American Journal of Occupational Therapy* 61, no. 3: 290–302.
- Gadamer, H.-G. 2007. *Sandhed og metode: grundtræk af en filosofisk hermeneutik* [Truth and method]. Copenhagen: Akademia.
- Goodacre, L. 2006. Women's perceptions on managing chronic arthritis. *British Journal of Occupational Therapy* 69, no. 1: 7–14.
- Gubrium, J., and J. Holstein. 1997. *The new language of qualitative method*. New York: Oxford University Press.
- Hammersley, M., and P. Atkinson. 2007. *Ethnography: Principles in practice*. 3<sup>rd</sup> ed. London: Routledge.
- Hasselkus, B.R. 2006. The world of everyday occupation: Real people, real lives. *The American Journal of Occupational Therapy* 60, no. 6: 627–40.
- Hastrup, K. 2003. *Ind i verden. En grundbok i antropologisk metode* [Anthropological method]. Copenhagen: Hans Reitzlers Forlag.
- Huibers, H., J. Marcus, and S. Wessely. 2006. The act of diagnosis: Pros and cons of labelling chronic fatigue syndrome. *Psychological Medicine* 36, no. 7: 895–900.
- Josephsson, S., E. Asaba, H. Jonsson, and S. Alsaker. 2006. Creativity and order in communication: Implications from philosophy to narrative research concerning human occupation. *Scandinavian Journal of Occupational Therapy* 13, no. 2: 125–32.
- Keponen, R., and G. Kielhofner. 2006. Occupation and meaning in the lives of women with chronic pain. *Scandinavian Journal of Occupational Therapy* 13: 211–20.
- Kielhofner, G. 2008. *Model of Human Occupation. Theory and Application* (Fourth edition ed.): Wolters Kluwer. Lippincott Williams and Wilkins.
- Kralik, D. 2002. The quest for ordinariness: Transition experienced by midlife women living with chronic illness. *Journal of Advanced Nursing* 39, no. 2: 146–54.
- Kralik, D., T. Koch, K. Price, and N. Howard. 2004. Chronic illness self-management: Taking action to create order. *Journal of Clinical Nursing* 13, no. 2: 259–67.
- Kvale, S. 1996. *Interviews: An introduction to qualitative research interviewing*. Thousand Oaks, CA: Sage.
- Kvien, T.K. 2004. Epidemiology and burden of illness of rheumatoid arthritis. *Pharmacoconomics* 22, suppl. 1: 1–12.
- Law, M. 2002. Participation in the occupations of everyday life. *American Journal of Occupational Therapy* 56, no. 6: 640–9.
- Lindseth, A., and A. Norberg. 2004. A phenomenological hermeneutical method for researching lived experience. *Scandinavian Journal of Caring Sciences* 18, no. 2: 145–53.
- Mattingly, C. 1998a. *Healing dramas and clinical plots. The narrative structure of experience*. Los Angeles: University of California Press.
- Mattingly, C. 1998b. In search of the good: Narrative reasoning in clinical practice. *Medical Anthropology* 12, no. 3: 273–97.
- Mattingly, C. 2006. Reading medicine: Mind, body, and meditation in one interpretive community. *New Literary History* 37, no. 3: 563–81.
- Nygren, B., A. Norberg, and B. Lundman. 2007. Inner strength as disclosed in narratives of the oldest old. *Qualitative Health Research* 17, no. 8: 1060–73.
- Paterson, B.L. 2003. The koala has claws: Applications of the shifting perspectives model in research of chronic illness. *Qualitative Health Research* 13, no. 7: 987–94.

- Polkinghorne, D. 1995. Narrative configuration in qualitative analyses. *Qualitative Studies in Education* 8, no. 1: 5–23.
- Polkinghorne, D. 1996. Transformativ narratives: From victimic to agentic life plots. *American Journal of Occupational Therapy* 50, no. 4: 299–305.
- Polkinghorne, D. 2004. *Practice and the human sciences. The case for a judgement-based practice of care*. New York: State University of New York Press.
- Ricoeur, P. 1984. *Time and narrative* vol. I. Chicago: The University of Chicago Press.
- Ricoeur, P. 1991. *From text to action: Essays in hermeneutics*. Evanston, IL: Northwestern University Press.
- Rosenfeld, D., and C. Faircloth. 2004. Embodied fluidity and the commitment to movement: Constructing the moral self through arthritis narratives. *Symbolic Interaction* 27, no. 4: 507–29.
- Sangha, O. 2000. Epidemiology of rheumatic diseases. *Rheumatology* 39, suppl. 2: 3–12.
- Stern, N.D. 2004. *The present moment in psychotherapy and everyday life*. New York: W.W.Norton.
- Stultjens, E., J. Dekker, L. Bouter, D. van Schaardenburg, M.-A. van Kuyk, and C. van den Ende. 2002. Occupational therapy for rheumatoid arthritis: A systematic review. *Arthritis and Rheumatism* 47, no. 6: 672–85.
- Thorne, S. 1999. The science of meaning in chronic illness. *International Journal of Nursing Studies* 36, no. 5: 397–404.
- Thorne, S., B. Paterson, S. Acorn, C. Canam, G. Joachim, and C. Jillings. 2002. Chronic illness experience: Insights from a metastudy. *Qualitative Health Research* 12, no. 4: 437–52.
- Thorne, S., B. Paterson, and C. Russell. 2003. The structure of everyday self-care decision making in chronic illness. *Qualitative Health Research* 13, no. 10: 1337–52.
- Townsend, A., S. Wyke, and K. Hunt. 2006. Self-managing and managing self: practical and moral dilemmas in accounts of living with chronic illness. *Chronic Illness* 2, no. 3: 185–94.
- Ville, I., and M. Khlat. 2007. Meaning and coherence of self and health: An approach based on narratives of life events. *Social Science and Medicine* 64, no. 4: 1001–14.
- Yang, L.H., A. Kleinman, B.G. Link, J.C. Phelan, S. Lee, and B. Good. 2007. Culture and stigma: Adding moral experience to stigma theory. *Social Science and Medicine* 64: 1524–35.
- Yoshida, K., and M. Stephens. 2004. Living with rheumatoid arthritis. Strategies that support independence and autonomy in everyday life. *Physiotherapy Theory and Practice* 20, no. 4: 221–31.
- Öhlen, J. 2003. Evocation of meaning through poetic condensation of narratives in empirical phenomenological inquiry into human suffering. *Qualitative Health Research* 13, no. 4: 557–66.