Experiences of health-promoting self-care in people living with rheumatic diseases

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Submitted on 16 Aug 2011

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<td>Manuscript/Short Report</td>
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Comments to decision letter

Manuscript ID JAN-2010-0160.R1

Comments to the Editor

Dear Editor,

Thank you for the positive response regarding our paper. All questions rose by you and the reviewer have been considered and the manuscript have been revised or commented accordingly to these. Hopefully you will now find that the manuscript is fulfilling requirements for publication in JAN.

1. I appreciate that English is not your first language. However, the English language and expression used in this paper is poor or incorrect in many places throughout. As the reviewer states this makes it hard for the reader to read and understand what your study is about. Publishers will not publish papers that do not have acceptable English. Can I suggest that you check throughout the paper that the English syntax, grammar, spelling, expression and meaning are clear and correct. On the JAN website guide to authors there is a help sheet on tips for writing. I suggest that you take a look at that. Also, you will need to have a person who is fluent in written and spoken English check and correct the paper, if necessary. We are unable to do this.

Our answer: The paper has now been scrutinised by a native English speaker and we hope you will find her work well.

2. Introduction. Instead of - In the world, suggest use Globally, there are over 150 known rheumatic diseases.........is better.

Our answer: “In the world” has been changed to “Globally” in accordance to recommendation.

3. Avoid using he/she use they instead.

Our answer: We are now using “they” throughout the paper.

4. Only use abbreviations when they have been written out in full first, as per convention. ....rheumatoid arthritis (RA)..... then go on to use abbreviation. Check this is the case in the Discussion section.

Our answer: Rheumatoid arthritis (RA) is first mentioned at page 6 and then we use RA in the Discussion.
Comments to reviewer 1

Dear reviewer 1,

Thank you for valuable comments and for finding our paper interesting. We hope that the following comments and our changes will fulfil the questions you raised.

This revised manuscript is improved in description of intent and methods, and its relevance for the care of people with rheumatic diseases is more clear. Overall, the paper remains difficult for the native English speaker, and it still needs significant editing for word usage, English grammar and sentence structure. The reader is frustrated by the fact that you know there is something very worthwhile within the paper, but it is very difficult to get at it because of the intensity of attention required.

Our answer: The paper has now been scrutinised by a native English speaker and we hope you will find her work well.

There are only two remaining substantive comments. In general, methodology is well described, but in the section on "Rigour", little is said about how credibility was established. Later, in "Study Limitations", conformity and dependability are alluded to. Please move the comments on conformity and dependability to the earlier section and describe how these were established.

Our answer: We have now tried to describe more in the section on "Rigour" about how credibility, conformity and dependability were established.

Second, conclusions are overdrawn. It is not reasonable at this point to extend the study findings to other people with rheumatic diseases. Although the authors have clarified the rationale for the purposive sampling approach, the sample is far too small (and the methods are qualitative) for generalizing the results to others.

Our answer: We have changed the conclusions.

Two other areas of discussion in which conclusions are not based on the study findings are:

1. page 17. No data are presented that lead to the conclusion that the specific diagnosis doesn't matter for the self-care experience. Although we know this is true from decades of stress and coping research (and was one of my original objections to this study in review of the first version), this study was not designed to demonstrate this proposition.

Our answer: We have removed these sentences.
2. page 19. There are no data presented related to self esteem, whether high or low, and even if they were, the study design would not permit conclusions about the influence of self esteem to be drawn.

Our answer: We have changed the sentences.
ABSTRACT

Title
Experiences of health-promoting self-care in people living with rheumatic diseases

Aim
This paper is a report of a study which explores and describes the meaning of the phenomenon health-promoting self-care as experienced by people living with rheumatic diseases.

Background
People with rheumatic diseases estimate health status as low and health belief and health status influence the self-care behaviours. Several self-care behaviours are used in the efforts to mitigate the diseases.

Method
The study had a descriptive phenomenological approach based on a reflective life-world perspective. Data were gathered in 2007 by unstructured open-ended interviews with 12 individuals living with rheumatic diseases.

Findings
The meaning of health-promoting self-care as experienced by people living with rheumatic diseases was that self-care takes place against a background of continual hope and belief to influence health in positive ways. Self-care was a way of life and implied being ready to understand and respond to signals from the body. Three inter-related constituents elucidated the experiences: dialogue, power struggle and choice. Self-care was experienced as dialogues
within the body and with the immediate environment. In order to respond to signals from the body, power struggles were required to be entered when fighting the diseases. Choices were required to be made and things that were beneficial for the body were prioritised.

Conclusion

In the present study the meaning of health-promoting self-care as experienced by people living with rheumatic diseases was that self-care was a way of life. It meant to be ready to understand and respond to signals from the body. Self-care required dialogues, power struggles and choices.

Keywords. Adults, health, nursing, phenomenology, rheumatic diseases, self-care.
SUMMARY STATEMENT

What is already known about this topic

- It is common that people with rheumatic diseases estimate their health status as low, and their health status and health belief influence the choice of self-care behaviours.
- People with rheumatic diseases can make use of several self-care behaviours in their efforts to mitigate the diseases.
- Self-care is a multi-dimensional and complex process for people with rheumatic diseases, where the purpose is to bring about order in their lives.

What this paper adds

- The meaning of health-promoting self-care as experienced by people living with rheumatic diseases was that self-care takes place against a background of continual hope and belief to influence health.
- Self-care was experienced as a way of life and meant to be ready to listen, understand and respond to signals from the body indicating well-being or discomfort.
- Three inter-related constituents elucidated the experiences of health-promoting self-care: dialogue, power struggle and choice.

Implications for practice and/or policy

- The findings give a new perspective of self-care which may deepen the understanding of health professionals, but are also beneficial and supportive to people living with rheumatic diseases.
- The perspective is important to take into account when planning and starting patient education about health-promoting self-care to people living with rheumatic diseases.
INTRODUCTION

Globally, there are over 150 rheumatic diseases with a great variation in terms of severity and complexity (WHO 2008). Living with rheumatic diseases can mean severe pain, negative feelings (like sadness, unfairness, guilt), but also a focus on managing and recovery from the disease (Hwang et al. 2004, Maly and Krupa 2007, Mitton et al. 2007). It is common that people with rheumatic diseases estimate their health status as low (Da Costa et al. 2000, Neumann et al. 2000). Health status and health belief (McDonald-Miszczak and Wister 2005), but also different cultural traditions have shown to influence choices of self-care behaviours in people with rheumatic diseases (Ibrahim et al. 2001, McDonald-Miszczak and Wister 2005). According to a caring perspective adults have the ability to act in order to maintain health and to treat themselves in the event of illness or injury (Orem 2001). These abilities are learned through relationships and communication with other people and are conscious acts (Denyes et al. 2001, Orem 2001).

In people with rheumatic diseases, self-care is a multi-dimensional and complex process with a purpose to bring about order in their life. The process involves recognising and monitoring boundaries of the body, mobilising resources, managing the shift in self-identity, as well as balancing, planning and prioritising in life (Kralik et al. 2004). It has been found that people with rheumatic diseases use several self-care behaviours in their efforts to mitigate the disease, maintain independence and prevent loss of valued life activities. Such self-care behaviours are, for example, adopting an acceptance of the disease, trying to have a positive attitude, exercising regularly, using alternative treatment methods and using distractions in activities that stimulate and maintain independence (Taylor 2001). People with rheumatic diseases learn how to respond to symptoms and consequences of the diseases by reflecting over the outcomes of successful or unsuccessful self-care behaviours (Kralik et al. 2004).
Thus, personal and social resources are important when trying to tolerate and manage the burden of the disease (Malterud and Hollnagel 2004).

The previous research performed in South Korea (Hwang et al. 2004), Canada (McDonald-Miszczak and Wister 2005), United Kingdom (Mitton et al. 2007), USA (Ibrahim et al. 2001), Australia (Kralik et al. 2004, Taylor 2001) and Norway (Malterud and Hollnagel 2004) shows that self-care is important for health in people with rheumatic diseases all over the world. Despite this there is little research from the perspective of how these people experience their self-care and what meaning they ascribe to self-care. From a clinical point of view and in order to increase the currently limited knowledge about why people with rheumatic diseases do not always do the recommended self-care, it is of interest to study how people living with rheumatic diseases experience health-promoting self-care.

THE STUDY

Aim

The aim of the study was to explore and describe the meaning of the phenomenon health-promoting self-care as experienced by people living with rheumatic diseases.

Design

The present study had a Husserlian phenomenological approach (Husserl 1913/2004) based on a reflective life-world perspective (Merleau-Ponty 1945/2004). The purpose of a phenomenological reflective life-world perspective is to come close to and describe the essence or general structure of the phenomenon in a clear and comprehensible way, to expand and deepen the understanding about the individual’s lived experience (Giorgi 2009, Dahlberg et al. 2008).
Participants

The inclusion criteria were that the individuals were registered as patients at a rheumatology unit in the southwest of Sweden, had for more than a year one or more diagnosis of rheumatic diseases, understood and spoke Swedish, and had not been cared for by the first author. In this purposeful sample the variations of experiences were guarantied by strategically selecting with regard to sex, age, rheumatic disease and ethnicity (Dahlberg et al. 2008). Thus, 12 individuals were strategically selected from the waiting list for regular visits to the rheumatologists. The mean age for the six women was 43 years (37-51 years) and for the six men the mean age was 55 years (39-73 years). Two of the individuals were born in other countries than Sweden, one from South America and one from Central Europe. The individuals’ diagnosed rheumatic diseases were ankylosing spondylitis, polyarthritis, polymyalgia rheumatica, psoriatic arthritis, rheumatoid arthritis (RA), reactive arthritis, scleroderma, Sjögren´s syndrome and systemic lupus erythematosus.

Data collection

The data collection took place January to May in 2007. All the individuals were called up by the first author in order to give information about the aim of the study and ask if they wanted to participate. The individuals received both verbal and written information about the voluntariness to participate, to withdraw from the study at any time and they were guaranteed confidentiality. All selected individuals chose to participate and written informed consent was gathered. The interviews were carried out by the first author in an undisturbed place in the individuals’ homes or at the rheumatology unit, but not in connection with any visit to caregivers. These interviews lasted between 80 to 135 minutes and were tape recorded.
According to a phenomenological approach the research interviews needed to be guided by openness and adherence to the phenomenon under study (Giorgi 1997, 2009, Dahlberg et al. 2008). An unstructured interview without beforehand framed questions were therefore used. All interviews started with an initial question: "Can you tell me about any situation where you felt that something you did was improving your health?" In order to reach depth in data and let the individuals reflect over their answers follow up questions like: “How do you think when you say ....?” and “What does it mean for you?” were asked.

**Ethical considerations**

This study conformed to the principles outlined in the Declaration of Helsinki (WMA 2008). The study was approved by the Ethics Research Committee, Faculty of Medicine, Lund University, Sweden, dnr 566/2006. All interviews were coded to protect the anonymity of the individuals and were transcribed verbatim by the first author. The translation of the interviews into English was made carefully so the original meaning was not altered.

**Data analysis**

The descriptive analysis of data material followed the phenomenological approach as described by Giorgi (1997, 2009) and Dahlberg et al. (2008). Initially, and in order to get an overall impression of the material, the interviews were intercepted and read several times until the authors felt familiar with the material. The sense of the whole was important before starting to examine the parts. Subsequently, each transcribed interview was divided into smaller parts, meaning-bearing units, in relation to the studied phenomenon health-promoting self-care. Based on the variations of differences and similarities, the meaning-bearing units were organised in order to see and understand patterns, clusters of meanings (Dahlberg et al. 2008). As the analysing process moved forward from concreteness to a more abstract level of
understanding the clusters of meanings were synthesised into a structure or pattern in which they were bound together. In this phase the essence of the phenomenon health-promoting self-care started to emerge. The essence, the very core of the phenomenon and its constituents with an aim to describe and clarify the essence, were thus analysed in relation to each interview, meaning-bearing units and clusters of meanings. The constituents could not be separated; they were intertwined with each other, as well as with the essence (Dahlberg et al. 2008).

According to a phenomenological approach, data were openly analysed by flexible moving between the whole – the parts – the whole of the interviews (Giorgi 1997, 2009, Dahlberg et al. 2008).

Rigour

The phenomenological method was chosen due to its openness and strength in describing experiences without attempting to interpret them (Dahlberg et al. 2008). The credibility was strengthened when the last author scrutinised every transcribed interview before the next interview was done by the first author, to be sure that the questions in the interviews were in accordance with the aim of the study. The sample size was not decided on beforehand, but was determined from to what extent the individuals had the ability to provide rich and deep data. To strengthen the dependability the first and last author, which were familiar with the method, began to analyse the data separately and then they compared the compliance of the findings. The conformability of the results was considered in all stages of the study when the authors tried to restrain or bracket their pre-understanding due to, for instance, their experiences of working with rheumatology care, living with a rheumatic disease or having relatives or friends who were living with a rheumatic disease (Polit and Beck, 2010). All authors had different professional, clinical and theoretical background, and were involved in most steps of the study. The authors’ personal beliefs, theories and assumptions were always
put under consideration and critical reflexion in order to encounter data in an open manner (Giorgi 1997, 2009).

**FINDINGS**

Initially in the findings section the essence of the phenomenon health-promoting self-care in people living with rheumatic diseases will be presented. The essence is followed by its three constituents, dialogue, power struggle and choice, which describe and clarify the essence. The constituents are described and illustrated by quotations from the interviews.

**The essence of the phenomenon health-promoting self-care**

For people living with rheumatic diseases, self-care takes place against a background of continual hope and belief in a future ability to influence health in a positive way. Health is experienced as a harmony and to be in balance with the body, as well as in all other aspects of life like the individual’s social life.

Self-care is a way of life and means being ready at all times to respond to signals from the body, such as tiredness, sadness, stiffness, and pain. Such signals need to be interpreted and understood as indicators on actions that are needed to alleviate the problem(s). Self-care means an inner dialogue where physical, emotional, and cognitive aspects of the body are considered. It is equally a dialogue with previous social, cultural and religious memories, and experiences of life, as well as with other people such as family members, colleagues and friends, mass media, and written word in books or on the Internet.

The meaning of self-care can also be described as a power struggle within the individual between the desire to be free from the rheumatic disease and the concrete fact that the
symptoms indicate that the disease is a part of the body. People living with rheumatic diseases strive and force themselves to fight the illness and its concrete consequences in order to attain well-being and health. The power struggle takes place within the body, between its possibilities and limitations, and the meaning of the power struggle is to obtain control over the body.

The meaning of self-care is to make rewarding or beneficial choice. The choice implies a dialectic process where previous experiences are carefully balanced against the will to change and challenge the lack of well-being caused by the diseases. Trust in oneself and belief in one’s own ability to choose health-promoting self-care is crucial for the choice. Although the choice between different self-care approaches is not always clear and straightforward, the choice is invariably aimed at generating some form of recompenses for the body related to health and well-being. Rewarding or beneficial choice increase the self-confidence and the self-esteem.

Dialogue

The meaning of self-care for people living with rheumatic diseases is to be in a constant ongoing dialogue with the body, where emotions, thoughts and stimuli of the senses can be known and heard. The dialogue is experienced like an open attention to bodily signals by reasoning about, listening to, observing and analysing these. It occurs against the background of a desire to understand the signals’ origin and consequences. The dialogue reveals and highlights, for example, signals indicating well-being such as peacefulness and joy, as well as discomfort such as pain, feelings of weakness, and worry. The meaning of the dialogue is to evaluate various bodily signals in order to decide whether to apply previously used self-care
such as rest, walks and medication and/or whether to search for and test new forms of self-care.

*I noticed that I didn’t have the strength to prepare the food I wanted and needed… that my body needed, my cells needed to regenerate themselves. And then I started to read about nutrition…vitamins, minerals, everything about the cells //… Inner strength alone is not enough.* (Individual 5)

In the dialogue with the body, physical signals can sometimes dominate and the individual’s emotions and intentions are coming in the background. On these occasions, the body may be experienced as if the body has its own way of functioning. In order for the individuals to perform self-care, they need to understand how the restricted body functions. Understanding emerges in the dialogue and requires willingness, time, and ability to calmly listen and wait until the signals emitted by the body become clearer.

*I wait for it (the body). Yes, I brood and wait to see what will happen // …I just wait and try and see what kind of pain it is.* (Individual 3)

The dialogue sometimes demands silence. It facilitates the listening to the body. Silence make signals clearer and minimises risk of disregarding significant signals. When listening, the individual becomes observant and aware of both strong and weak signals of pleasure or discomfort emitted by the body. During the dialogue feelings of astonishment, joy, and frustration emerge, due to that the body does not react in its usual way.

*I pursued sports, exercised and things like that …and I always had setbacks in that my knees did not hold…while at the same time I felt that I needed to get some exercise.* (Individual 8)
On such occasions, the changeableness of the body and its unpredictability becomes obvious.

Learning on the basis of an understanding of one’s own body as being in a state of permanent transformation is one meaning of the dialogue. The dialogue can also arise in relation to the immediate environment, such as information from mass media, written texts in books, newspapers, and on the Internet, as well as in conversations with other people. Feelings of togetherness and fellowship emerge when being in a dialogue with others, whereby feelings of loneliness are eclipsed and a sense of being like others and being needed is created.

*Like the woman over there...we were having coffee and chatting about diseases.... That she was feeling so unwell and one thing and the other and she was so negative. ...But you can change it, I said... I try to turn it into something positive...actually... One tries to pep them up...and it makes me feel good too.* (Individual 7)

**Power struggle**

The meaning of self-care for people living with rheumatic diseases is a power struggle between the symptoms and consequences of the disease in everyday life, and the individual’s will to experience well-being and regain control over the body. The individual wages a battle against the health problems caused by the disease by sometimes limiting wishes, desires and urges as well as resisting temptations. The power struggle means negotiation between degrees of control and discipline with the urge to give into desires and wishes.

*When I put my foot outside the door I initially feel that I have no strength, but after having done my first round...my body gradually becomes warmer and then... My joints become more supple. Yes, my whole body feels lighter. // It's essential to go out. Irrespective of how you feel. You just have to make a move and do it.* (Individual 5)
The individual experiences being in control when the body responds to self-care in the way expected and the control has been preceded by searching for and challenging the boundaries of the body. The power struggle takes place within the body, i.e. between the physical body, soul and spirit in addition to the individual’s social life, a process that takes time.

_I can never let it (the disease) control me, I prefer to… test it… Then I'd rather go against it… and think that it cannot be that bad… for me… (Individual 12)_

The power struggle makes itself felt in the dialectics between the possibilities and limits of the body, which both generates and requires energy. When control is regained, it is experienced as a form of reward that generates energy. On the other hand, the power struggle drains energy, not least due to the willpower that must be mobilised and maintained. However, energy consumed by the power struggle is less than energy provided by the control obtained.

The meaning of the power struggle becomes visible in the event of failure to achieve control. When the latter occurs, it can generate a sense of a defeat as well as feelings of loss, disappointment and anger at being beaten by the disease. However, over time defeat can generate energy to start a new power struggle, not least when knowledge about new self-care opportunities is gained in the interplay with the body, other people and written texts.

_I went to the library and found this book (about training)... Very strange training indeed... Had not seen anything like it... I brought it home and started to read, it felt odd... Didn’t understand at first... Then I began to go out walking, train...//... Then the pain in my back started to go away... then I learned...this. I received the support I needed. (Individual 5)_

When the self-care is not the individual’s own choice, such as to take some sort of medicine, it may be experienced as if self-care is forced upon them, as being demanding and sometimes frightening. The power struggle that arises reveals above all the unequal relationship between
the individual’s will to be free from the disease and the objective reality of being afflicted by a rheumatic disease and thus being forced to take medication. The inequality prompts the individual to find courage to fight, as difficult decisions have to be made, whether to accept or refuse medication. The unequal power struggle also exposes the vulnerability of the individual, such as uncertainty about the future consequences of a decision regarding medication. The uncertainty is sometimes experienced as powerlessness and as reducing the scope for choice in relation to self-care.

It feels as if I don’t have many alternatives really... I know that it would be very much worse without them (Humira)... But it’s a bit scary, because you don’t really know what the side-effects are... and those drugs are fairly new... So of course you think about it. I don’t think there is very much that I can choose between... actually... (Individual 10)

Choice

The meaning of self-care for people living with rheumatic diseases involves a process of making continuous choices, about whether or not to perform self-care or whether or not to listen to the signals of the body or the immediate environment. The choice is governed by positive or negative experiences of previous self-care, as well as the will to change and challenge ill health caused by the disease. The choice demands, as well as generates trust and belief in a person’s own ability and knowledge about how one’s body is functioning.

It (the chosen training) has taught me, I have learnt about me. About my body. I am at one with my body. I don’t leave my body in the hands of other people. I’m working with it and see the difference ...in the mirror. (Individual 5)

When making choice, the individual prioritised self-care that generates joy, energy and satisfaction as a result of, for example, reduced pain and stiffness, i.e. self-care that is
experienced as a reward and/or a beneficial for the body. These experiences of different 
rewards and benefits govern future choices of self-care and afford trust and belief in a 
person’s own ability to choose self-care that promotes well-being.

Sometimes you actually have to struggle to achieve certain goals. Sometimes it can be worth 
it. It’s like those who… climb Mount Everest. It’s hard work… But when they get their 
rewards… When they have reached the summit… Then it’s a feeling of freedom… And 
strength… Every step you take leads to an experience of being rewarded. (Individual 9)

When the choice of self-care fails to generate a benefit or reward for the body, a feeling of 
powerlessness emerges. The individual has to make a halt and start a dialogue with the body 
to find out what the next choice shall be. Sometimes the choice stands between safe and 
familiar self-care or more exciting and untested self-care. The choice of safe, familiar and 
well-tested self-care means that there is an assumption about the body to be predictable. The 
choice gives desired effects, whereas the choice of exciting and untested self-care is driven by 
a hope of finding new ways of overcoming the disease. This means an uncertainty and risk-
taking, although experienced as stimulating, mainly because the outcome can be a positive 
surprise.

She (a zone therapist) talks a lot about her natural cures and suchlike. And I couldn’t do like 
this (raises one arm)… so I started to go to her and attended five treatment sessions and 
received a bottle of pills and I haven’t had the problem since. As I got rid of the problem, 
what am I to think? After all, I have to believe in it, I only did it once…and it worked. 
(Individual 11)

The meaning of the choice is to try and challenge the safe, familiar and well-tested self-care, 
but also sometimes dare to combine it with exciting and untested self-care in an unfamiliar
territory. The choice of self-care is influenced by many factors; in addition to previous experiences, it can also be affected by how previous generations of the individual’s family dealt with ill health and achieved well-being.

I don’t know how I became aware of that resting …I suppose I was tired then (at noon), (laughing)...and wanted to have a rest. My grandparents always did that. They toiled and worked hard and were farmers. And they always took a rest after dinner. Took a break then, a siesta… // After eating and digesting, I feel better when I have rested for a while. I actually think it’s good. (Individual 2)

The meaning of the choice is also to lessen monotony and boringness in self-care. The choice of self-care is not governed by knowledge about the most suitable form, but by whether or not it is experienced as enjoyable and inspiring for the body. When making the choice the individuals are especially concerned not to experience themselves as ill, they want to be like everyone else.

I think that you feel more ill when you go there (the physiotherapy at the health care centre)... than when attending an ordinary gym. ...You feel that you are...the same as everybody else in an ordinary gym...even if you can’t lift as much. But when you are here, only cripples come here… Then you feel that, I come here because I’m ill… And when you feel after three weeks that the condition hasn’t improved, you feel… I won’t bother to go… I can go to an ordinary gym and feel... I can manage it all right. But I still haven’t managed to improve those small muscles that she (the physiotherapist) is after…but I can manage regardless. (Individual 12)

DISCUSSION

Study limitations
To some extent only 12 individuals being interviewed may be seen as a limitation, but the
interviews presented a comprehensive amount of meanings of the phenomenon health-
promoting self-care. The authors are therefore inclined to believe that the result presented
here is of interest to health-care professionals and other people with rheumatic diseases.

Experiences of the phenomenon health-promoting self-care

New in the present study is that people who lived with rheumatic diseases experienced the
phenomenon health-promoting self-care as a way of life and that it meant to be ready at all
times to understand and respond to signals that the body sends out. The self-care required that
dialogues, power struggles and choices were made. The background to the self-care was a
continual hope and belief in the own ability to influence the health in a positive way. This
continual hope and belief means that self-care is constantly in progress and development, and
that the individuals exhibit a tremendous capacity.

The findings from the present study agreed well with Orem’s self-care theory which describes
self-care as a process. This process consists of actions of investigating, formulating and
expressing requirements, but also making judgements about what should be done. When
individuals perform actions it requires essential power which was activated through stimuli
(Denyes et al. 2001, Orem 2001). In the present study self-care was described as a power
struggle between the individual and the rheumatic diseases, but also in relation to other
people. The power struggle was within the body, between its possibilities and limitations, and
the meaning was to obtain control over the body. This is a finding supported by Kralik et al.
(2004) and Taylor (2001) who demonstrated that self-care was a constant planning and
managing of daily life as a meaning of creating order. The present study and Kralik et al.
(2004) show that action to initiate order or obtain control is not a single act; instead it is a combination of processes carried out over a period of time.

In the present study health-promoting self-care as experienced by people living with rheumatic diseases also required that they made choices which essential means were to generate some form of reward for the body in order to increase the possibilities to improve the well-being and health. These choices in turn required that previous experiences were balanced carefully against the desire to change and challenge the lack of well-being caused by the diseases. This agreed well with the findings from Kralik et al. (2004) where people learned about their responses to diseases through the experiences and as a result of trial and error. They learned about their personal limitations or boundaries and could then make decisions how they should plan and prioritise (Kralik et al. 2004). In order to experience good health, people with various disabilities need the ability to build and maintain a sense of balance between body, mind and spirit, as well as between their social context and environment (Albrecht and Devlieger 1999). This agreed well with the findings from the present study where the individuals experienced health as a harmony and to be in a balance with the body. The body means a unit of the physical body and soul, as well as the individual’s social life. The individuals experienced that the body could not be shared in various parts - everything was connected. Their experiences agreed well with Merleau-Ponty’s philosophy where the physical and the psychological are described as an interwoven unit, the lived body. The lived body is then in constant interaction with the world (Merleau-Ponty 1945/2004).

In the present study health-promoting self-care as experienced by people living with rheumatic diseases required trust in oneself and belief in one’s own ability to make choices. Backman and Hentinen (2001) have found that high self-esteem was predicting a responsible
self-care behaviour style. Feeling of togetherness, fellowship and being like others were important for the choice of self-care in the present study and two other studies found that the individuals acquired a power of life from people around them (Hwang et al. 2004, Hadert and Rodham 2008). This was also in agreement with Malterud and Hollnagel’s (2004) findings where personal and social resources were essential means for tolerating and managing the burden of diseases.

Previous research has shown the effectiveness of exercise on health for people with RA, but the evidence for other self-care interventions has been absent or weak (Vliet Vlieland 2007). The present study offers new insights about self-care. The meaning of self-care was much more than exercise. Self-care was an internal dialogue within the body, but also an external dialogue with the immediate environment. In order for the individuals to perform self-care, they needed to understand how the restricted body functioned. This understanding required time, willingness, and the ability to wait in an active way until the signals emitted by the body became clearer. Often there is no time in clinical practice to give patients the opportunity to have internal and external dialogues; instead there is often an unspoken requirement on the patient to listen, accept and to do what is recommended (Arborelius 2001). It has been shown that patients with RA wants to be informed and that they express a great need for information about the disease and its treatments (Neame et al. 2005), but they do not always understand the information (Hadert and Rodham 2008). It is important that health-care professionals find ways of checking the level of patients’ understanding and only after that they could support and empower the patients to do self-care (Hadert and Rodham 2008). All these findings can be useful to bring into rheumatology care and our claim is that the new knowledge from the present study can be beneficial to health-care professionals. Unfortunately, there is a great lack of studies about how to take advantage of the individual’s personal and social resources.
CONCLUSION

In the present study the meaning of the phenomenon health-promoting self-care as experienced by people living with rheumatic diseases was that self-care was a way of life, and it meant to be ready at all times to understand and respond to signals from the body. Self-care required dialogues, power struggles and choices. Further studies are needed to find the best way in clinical practice to support patients with rheumatic diseases to do and be able to continue with health-promoting self-care.

COMPETING INTERESTS

The authors declare that they had no competing interests.
REFERENCES


ABSTRACT

Title
Experiences of health-promoting self-care in people living with rheumatic diseases

Aim
This paper is a report of a study which explores and describes the meaning of the phenomenon health-promoting self-care as experienced by people living with rheumatic diseases.

Background
People with rheumatic diseases estimate health status as low and health belief and health status influence self-care behaviours. Several self-care behaviours are used in the efforts to mitigate the diseases.

Method
The study had a descriptive phenomenological approach based on a reflective life-world perspective. Data were gathered in 2007 by unstructured open-ended interviews with 12 individuals living with rheumatic diseases.

Findings
The meaning of health-promoting self-care as experienced by people living with rheumatic diseases was that self-care takes place against a background of continual hope and belief to influence health in positive ways. Self-care was a way of life and implied being ready to understand and respond to signals from the body. Three inter-related constituents elucidated their experiences: dialogue, power struggle and choice. Self-care was experienced as
dialogues within the body and with the immediate environment. In order to respond to signals from the body, power struggles were required to be entered into when fighting the diseases. Choices were required to be made and things that were beneficial for the body were prioritised.

Conclusion

In the present study the meaning of health-promoting self-care as experienced by people living with rheumatic diseases was that self-care was a way of life. It meant to be ready to understand and respond to signals from the body. Self-care required dialogues, power struggles and choices.

Keywords. Adults, health, nursing, phenomenology, rheumatic diseases, self-care.
SUMMARY STATEMENT

What is already known about this topic

- It is common that people with rheumatic diseases estimate their health status as low, and their health status and health belief influence the choice of self-care behaviours.

- People with rheumatic diseases can make use of several self-care behaviours in their efforts to mitigate the diseases.

- Self-care is a multi-dimensional and complex process for people with rheumatic diseases, where the purpose is to bring about order in their lives.

What this paper adds

- The meaning of health-promoting self-care as experienced by people living with rheumatic diseases was that self-care takes place against a background of continual hope and belief to influence health.

- Self-care was experienced as a way of life and meant to be ready to listen, understand and respond to signals from the body indicating well-being or discomfort.

- Three inter-related constituents elucidated the experiences of health-promoting self-care: dialogue, power struggle and choice.

Implications for practice and/or policy

- The findings give a new perspective of self-care which may deepen the understanding of health professionals, but are also beneficial and supportive to people living with rheumatic diseases.

- The perspective is important to take into account when planning and starting patient education about health-promoting self-care to people living with rheumatic diseases.
INTRODUCTION

Globally, there are over 150 rheumatic diseases with a great variation in terms of severity and complexity (WHO 2008). Living with rheumatic diseases can mean severe pain, negative feelings (like sadness, unfairness, guilt), but also a focus on managing and recovery from the disease (Hwang et al. 2004, Maly and Krupa 2007, Mitton et al. 2007). It is common that people with rheumatic diseases estimate their health status as low (Da Costa et al. 2000, Neumann et al. 2000). Health status and health belief (McDonald-Miszczak and Wister 2005), but also different cultural traditions have been shown to influence choices of self-care behaviours in people with rheumatic diseases (Ibrahim et al. 2001, McDonald-Miszczak and Wister 2005). According to a caring perspective adults have the ability to act in order to maintain health and to treat themselves in the event of illness or injury (Orem 2001). These abilities are learned through relationships and communication with other people and are conscious acts (Denyes et al. 2001, Orem 2001).

In people with rheumatic diseases, self-care is a multi-dimensional and complex process with a purpose to bring about order in their life. The process involves recognising and monitoring boundaries of the body, mobilising resources, managing the shift in self-identity, as well as balancing, planning and prioritising in life (Kralik et al. 2004). It has been found that people with rheumatic diseases use several self-care behaviours in their efforts to mitigate the disease, maintain independence and prevent loss of valued life activities. Such self-care behaviours are, for example, adopting an acceptance of the disease, trying to have a positive attitude, exercising regularly, using alternative treatment methods and using distractions in activities that stimulate and maintain independence (Taylor 2001). People with rheumatic diseases learn how to respond to symptoms and consequences of the diseases by reflecting over the outcomes of successful or unsuccessful self-care behaviours (Kralik et al. 2004).
Thus, personal and social resources are important when trying to tolerate and manage the burden of the disease (Malterud and Hollnagel 2004).

The previous research performed in South Korea (Hwang et al. 2004), Canada (McDonald-Miszczak and Wister 2005), United Kingdom (Mitton et al. 2007), USA (Ibrahim et al. 2001), Australia (Kralik et al. 2004, Taylor 2001) and Norway (Malterud and Hollnagel 2004) shows that self-care is important for health in people with rheumatic diseases all over the world. Despite this there is little research from the perspective of how these people experience their self-care and what meaning they ascribe to self-care. From a clinical point of view and in order to increase the currently limited knowledge about why people with rheumatic diseases do not always do the recommended self-care, it is of interest to study how people living with rheumatic diseases experience health-promoting self-care.

THE STUDY

Aim

The aim of the study was to explore and describe the meaning of the phenomenon health-promoting self-care as experienced by people living with rheumatic diseases.

Design

The present study had a Husserlian phenomenological approach (Husserl 1913/2004) based on a reflective life-world perspective (Merleau-Ponty 1945/2004). The purpose of a phenomenological reflective life-world perspective is to come close to and describe the essence or general structure of the phenomenon in a clear and comprehensible way, to expand and deepen the understanding about the individual’s lived experience (Giorgi 2009, Dahlberg et al. 2008).
Participants

The inclusion criteria were that the individuals were registered as patients at a rheumatology unit in the southwest of Sweden, had for more than a year one or more diagnosis of rheumatic diseases, understood and spoke Swedish, and had not been cared for by the first author. In this purposeful sample the variations of experiences were guaranteed by strategically selecting with regard to sex, age, rheumatic disease and ethnicity (Dahlberg et al. 2008). Thus, 12 individuals were strategically selected from the waiting list for regular visits to the rheumatologists. The mean age for the six women was 43 years (37-51 years) and for the six men the mean age was 55 years (39-73 years). Two of the individuals were born in other countries than Sweden, one from South America and one from Central Europe. The individuals’ diagnosed rheumatic diseases were ankylosing spondylitis, polyarthritis, polymyalgia rheumatica, psoriatic arthritis, rheumatoid arthritis (RA), reactive arthritis, scleroderma, Sjögren’s syndrome and systemic lupus erythematosus.

Data collection

The data collection took place January to May in 2007. All the individuals were telephoned by the first author in order to give information about the aim of the study and ask if they wanted to participate. The individuals received both verbal and written information about the voluntariness to participate, to withdraw from the study at any time and they were guaranteed confidentiality. All selected individuals chose to participate and written informed consent was obtained. The interviews were carried out by the first author in an undisturbed place in the individuals’ homes or at the rheumatology unit, but not in connection with any visit to caregivers. These interviews lasted between 80 to 135 minutes and were tape recorded.
According to a phenomenological approach the research interviews needed to be guided by openness and adherence to the phenomenon under study (Giorgi 1997, 2009, Dahlberg et al. 2008). **Unstructured interviews were therefore used.** All interviews started with an initial question: "Can you tell me about any situation where you felt that something you did was improving your health?" In order to reach depth in data and let the individuals reflect over their answers follow up questions like: “How do you think when you say ....?” and “What does it mean for you?” were asked.

**Ethical considerations**

This study conformed to the principles outlined in the Declaration of Helsinki (WMA 2008). The study was approved by the Ethics Research Committee, Faculty of Medicine, Lund University, Sweden, dnr 566/2006. All interviews were coded to protect the anonymity of the individuals and were transcribed verbatim by the first author. The translation of the interviews into English was made carefully so the original meaning was not altered.

**Data analysis**

The descriptive analysis of data material followed the phenomenological approach as described by Giorgi (1997, 2009) and Dahlberg et al. (2008). Initially, and in order to gain an overall impression of the material, the interviews were intercepted and read several times until the authors felt familiar with the material. The sense of the whole was important before starting to examine the parts. Subsequently, each transcribed interview was divided into smaller parts, meaning-bearing units, in relation to the studied phenomenon health-promoting self-care. Based on the variations of differences and similarities, the meaning-bearing units were organised in order to see and understand patterns, clusters of meanings (Dahlberg et al. 2008). As the analysing process moved forward from concreteness to a more abstract level of
understanding the clusters of meanings were synthesised into a structure or pattern in which they were bound together. In this phase the essence of the phenomenon health-promoting self-care started to emerge. The essence, the very core of the phenomenon and its constituents with an aim to describe and clarify the essence, were thus analysed in relation to each interview, meaning-bearing units and clusters of meanings. The constituents could not be separated; they were intertwined with each other, as well as with the essence (Dahlberg et al. 2008).

According to a phenomenological approach, data were openly analysed by flexible moving between the whole – the parts – the whole of the interviews (Giorgi 1997, 2009, Dahlberg et al. 2008).

Rigour

The phenomenological method was chosen due to its openness and strength in describing experiences without attempting to interpret them (Dahlberg et al. 2008). The credibility was strengthened when the last author scrutinised every transcribed interview before the next interview was done by the first author, to be sure that the questions in the interviews were in accordance with the aim of the study. The sample size was not decided on beforehand, but was determined to the extent the individuals had the ability to provide rich and deep data. To strengthen the dependability the first and last author, who were familiar with the method, began to analyse the data separately and then they compared the concordance of the findings. The conformability of the results was considered in all stages of the study when the authors tried to restrain or bracket their pre-understanding due to, for instance, their experiences of working with rheumatology care, living with a rheumatic disease or having relatives or friends who were living with a rheumatic disease (Polit and Beck, 2010). All authors had different professional, clinical and theoretical background, and were involved in most steps of the study. The authors’ personal beliefs, theories and assumptions were always put under
consideration and critical reflection in order to encounter data in an open manner (Giorgi 1997, 2009).

**FINDINGS**

Initially in the findings section the essence of the phenomenon health-promoting self-care in people living with rheumatic diseases will be presented. The essence is followed by its three constituents, dialogue, power struggle and choice, which describe and clarify the essence. The constituents are described and illustrated by quotations from the interviews.

**The essence of the phenomenon health-promoting self-care**

For people living with rheumatic diseases, self-care takes place against a background of continual hope and belief in a future ability to influence health in a positive way. Health is experienced as a harmony and to be in balance with the body, as well as in all other aspects of life like the individual’s social life.

Self-care is a way of life and means being ready at all times to respond to signals from the body, such as tiredness, sadness, stiffness, and pain. Such signals need to be interpreted and understood as indicators on actions that are needed to alleviate the problem(s). Self-care means an inner dialogue where physical, emotional, and cognitive aspects of the body are considered. It is equally a dialogue with previous social, cultural and religious memories, and experiences of life, as well as with other people such as family members, colleagues and friends, mass media, and written word in books or on the Internet.

The meaning of self-care can also be described as a power struggle within the individual between the desire to be free from the rheumatic disease and the concrete fact that the
symptoms indicate that the disease is a part of the body. People living with rheumatic diseases strive and force themselves to fight the illness and its concrete consequences in order to attain well-being and health. The power struggle takes place within the body, between its possibilities and limitations, and the meaning of the power struggle is to obtain control over the body.

The meaning of self-care is to make rewarding or beneficial choice. The choice implies a dialectic process where previous experiences are carefully balanced against the will to change and challenge the lack of well-being caused by the diseases. Trust in oneself and belief in one’s own ability to choose health-promoting self-care is crucial for the choice. Although the choice between different self-care approaches is not always clear and straightforward, the choice is invariably aimed at generating some form of recompenses for the body related to health and well-being. Rewarding or beneficial choice increase the self-confidence and the self-esteem.

Dialogue

The meaning of self-care for people living with rheumatic diseases is to be in a constant ongoing dialogue with the body, where emotions, thoughts and stimuli of the senses can be known and heard. The dialogue is experienced like an open attention to bodily signals by reasoning about, listening to, observing and analysing these. It occurs against the background of a desire to understand the signals’ origin and consequences. The dialogue reveals and highlights, for example, signals indicating well-being such as peacefulness and joy, as well as discomfort such as pain, feelings of weakness, and worry. The meaning of the dialogue is to evaluate various bodily signals in order to decide whether to apply previously used self-care
such as rest, walks and medication and/or whether to search for and test new forms of self-
care.

*I noticed that I didn’t have the strength to prepare the food I wanted and needed... that my
body needed, my cells needed to regenerate themselves. And then I started to read about
nutrition... vitamins, minerals, everything about the cells //... Inner strength alone is not
enough. (Individual 5)*

In the dialogue with the body, physical signals can sometimes dominate and the individual’s
ingeasure and intentions are coming in the background. On these occasions, the body may be
experienced as if the body has its own way of functioning. In order for the individuals to
perform self-care, they need to understand how the restricted body functions. Understanding
emerges in the dialogue and requires willingness, time, and ability to calmly listen and wait
until the signals emitted by the body become clearer.

*I wait for it (the body). Yes, I brood and wait to see what will happen // ...I just wait and try
and see what kind of pain it is. (Individual 3)*

The dialogue sometimes demands silence. It facilitates the listening to the body. Silence make
signals clearer and minimises risk of disregarding significant signals. When listening, the
individual becomes observant and aware of both strong and weak signals of pleasure or
discomfort emitted by the body. During the dialogue feelings of astonishment, joy, and
frustration emerge, due to that the body does not react in its usual way.

*I pursued sports, exercised and things like that ...and I always had setbacks in that my knees
did not hold...while at the same time I felt that I needed to get some exercise. (Individual 8)*
On such occasions, the changeableness of the body and its unpredictability becomes obvious.

Learning on the basis of an understanding of one’s own body as being in a state of permanent transformation is one meaning of the dialogue. The dialogue can also arise in relation to the immediate environment, such as information from mass media, written texts in books, newspapers, and on the Internet, as well as in conversations with other people. Feelings of togetherness and fellowship emerge when being in a dialogue with others, whereby feelings of loneliness are eclipsed and a sense of being like others and being needed is created.

Like the woman over there...we were having coffee and chatting about diseases.... That she was feeling so unwell and one thing and the other and she was so negative. ...But you can change it, I said... I try to turn it into something positive...actually... One tries to pep them up...and it makes me feel good too. (Individual 7)

Power struggle

The meaning of self-care for people living with rheumatic diseases is a power struggle between the symptoms and consequences of the disease in everyday life, and the individual’s will to experience well-being and regain control over the body. The individual wages a battle against the health problems caused by the disease by sometimes limiting wishes, desires and urges as well as resisting temptations. The power struggle means negotiation between degrees of control and discipline with the urge to give into desires and wishes.

When I put my foot outside the door I initially feel that I have no strength, but after having done my first round...my body gradually becomes warmer and then... My joints become more supple. Yes, my whole body feels lighter. // It’s essential to go out. Irrespective of how you feel. You just have to make a move and do it. (Individual 5)
The individual experiences being in control when the body responds to self-care in the way expected and the control has been preceded by searching for and challenging the boundaries of the body. The power struggle takes place within the body, i.e. between the physical body, soul and spirit in addition to the individual’s social life, a process that takes time.

*I can never let it (the disease) control me, I prefer to…test it… …Then I’d rather go against it…and think that it cannot be that bad… for me… (Individual 12)*

The power struggle makes itself felt in the dialectics between the possibilities and limits of the body, which both generates and requires energy. When control is regained, it is experienced as a form of reward that generates energy. On the other hand, the power struggle drains energy, not least due to the willpower that must be mobilised and maintained. However, energy consumed by the power struggle is less than energy provided by the control obtained.

The meaning of the power struggle becomes visible in the event of failure to achieve control. When the latter occurs, it can generate a sense of a defeat as well as feelings of loss, disappointment and anger at being beaten by the disease. However, over time defeat can generate energy to start a new power struggle, not least when knowledge about new self-care opportunities is gained in the interplay with the body, other people and written texts.

*I went to the library and found this book (about training)... Very strange training indeed… Had not seen anything like it… I brought it home and started to read, it felt odd … Didn’t understand at first… Then I began to go out walking, train…// …Then the pain in my back started to go away… then I learned…this. I received the support I needed. (Individual 5)*

When the self-care is not the individual’s own choice, such as to take some sort of medicine, it may be experienced as if self-care is forced upon them, as being demanding and sometimes frightening. The power struggle that arises reveals above all the unequal relationship between
the individual’s will to be free from the disease and the objective reality of being afflicted by a rheumatic disease and thus being forced to take medication. The inequality prompts the individual to find courage to fight, as difficult decisions have to be made, whether to accept or refuse medication. The unequal power struggle also exposes the vulnerability of the individual, such as uncertainty about the future consequences of a decision regarding medication. The uncertainty is sometimes experienced as powerlessness and as reducing the scope for choice in relation to self-care.

*It feels as if I don’t have many alternatives really... I know that it would be very much worse without them (Humira)… But it’s a bit scary, because you don’t really know what the side-effects are… and those drugs are fairly new… So of course you think about it. I don’t think there is very much that I can choose between... actually… (Individual 10)*

**Choice**

The meaning of self-care for people living with rheumatic diseases involves a process of making continuous choices, about whether or not to perform self-care or whether or not to listen to the signals of the body or the immediate environment. The choice is governed by positive or negative experiences of previous self-care, as well as the will to change and challenge ill health caused by the disease. The choice demands, as well as generates trust and belief in a person’s own ability and knowledge about how one’s body is functioning.

*It (the chosen training) has taught me, I have learnt about me. About my body. I am at one with my body. I don’t leave my body in the hands of other people. I’m working with it and see the difference …in the mirror. (Individual 5)*

When making choice, the individual prioritised self-care that generates joy, energy and satisfaction as a result of, for example, reduced pain and stiffness, i.e. self-care that is
experienced as a reward and/or a beneficial for the body. These experiences of different
rewards and benefits govern future choices of self-care and afford trust and belief in a
person’s own ability to choose self-care that promotes well-being.

Sometimes you actually have to struggle to achieve certain goals. Sometimes it can be worth
it. It’s like those who... climb Mount Everest. It’s hard work... But when they get their
rewards... When they have reached the summit... Then it’s a feeling of freedom... And
strength... Every step you take leads to an experience of being rewarded. (Individual 9)

When the choice of self-care fails to generate a benefit or reward for the body, a feeling of
powerlessness emerges. The individual has to make a halt and start a dialogue with the body
to find out what the next choice shall be. Sometimes the choice stands between safe and
familiar self-care or more exciting and untested self-care. The choice of safe, familiar and
well-tested self-care means that there is an assumption about the body to be predictable. The
choice gives desired effects, whereas the choice of exciting and untested self-care is driven by
a hope of finding new ways of overcoming the disease. This means an uncertainty and risk-
taking, although experienced as stimulating, mainly because the outcome can be a positive
surprise.

She (a zone therapist) talks a lot about her natural cures and suchlike. And I couldn’t do like
this (raises one arm)... so I started to go to her and attended five treatment sessions and
received a bottle of pills and I haven’t had the problem since. As I got rid of the problem,
what am I to think? After all, I have to believe in it, I only did it once...and it worked.
(Individual 11)

The meaning of the choice is to try and challenge the safe, familiar and well-tested self-care,
but also sometimes dare to combine it with exciting and untested self-care in an unfamiliar
territory. The choice of self-care is influenced by many factors; in addition to previous experiences, it can also be affected by how previous generations of the individual’s family dealt with ill health and achieved well-being.

_I don’t know how I became aware of that resting …I suppose I was tired then (at noon), (laughing).…and wanted to have a rest. My grandparents always did that. They toiled and worked hard and were farmers. And they always took a rest after dinner. Took a break then, a siesta… // After eating and digesting, I feel better when I have rested for a while. I actually think it’s good._ (Individual 2)

The meaning of the choice is also to lessen monotony and boredom in self-care. The choice of self-care is not governed by knowledge about the most suitable form, but by whether or not it is experienced as enjoyable and inspiring for the body. When making the choice the individuals are especially concerned not to experience themselves as ill, they want to be like everyone else.

_I think that you feel more ill when you go there (the physiotherapy at the health care centre)… than when attending an ordinary gym. …You feel that you are…the same as everybody else in an ordinary gym…even if you can’t lift as much. But when you are here, only cripples come here… Then you feel that, I come here because I’m ill… And when you feel after three weeks that the condition hasn’t improved, you feel… I won’t bother to go… I can go to an ordinary gym and feel… I can manage it all right. But I still haven’t managed to improve those small muscles that she (the physiotherapist) is after…but I can manage regardless._ (Individual 12)

**DISCUSSION**

**Study limitations**
To some extent only 12 individuals being interviewed may be seen as a limitation, but the interviews presented a comprehensive amount of meanings of the phenomenon health-promoting self-care. The authors are therefore inclined to believe that the result presented here is of interest to health-care professionals and other people with rheumatic diseases.

**Experiences of the phenomenon health-promoting self-care**

New in the present study is that people who lived with rheumatic diseases experienced the phenomenon health-promoting self-care as a way of life and that it meant to be ready at all times to understand and respond to signals that the body sends out. The self-care required that dialogues, power struggles and choices were made. The background to the self-care was a continual hope and belief in their ability to influence the health in a positive way. This continual hope and belief means that self-care is constantly in progress and development, and that the individuals exhibit a tremendous capacity.

The findings from the present study agreed well with Orem’s self-care theory which describes self-care as a process. This process consists of actions of investigating, formulating and expressing requirements, but also making judgements about what should be done. When individuals perform actions it requires essential power which was activated through stimuli (Denyes et al. 2001, Orem 2001). In the present study self-care was described as a power struggle between the individual and the rheumatic diseases, but also in relation to other people. The power struggle was within the body, between its possibilities and limitations, and the meaning was to obtain control over the body. This is a finding supported by Kralik et al. (2004) and Taylor (2001) who demonstrated that self-care was a constant planning and managing of daily life as a meaning of creating order. The present study and Kralik et al.
(2004) show that action to initiate order or obtain control is not a single act; instead is it a combination of processes carried out over a period of time.

In the present study health-promoting self-care as experienced by people living with rheumatic diseases also required that they made choices which essential means were to generate some form of reward for the body in order to increase the possibilities to improve the well-being and health. These choices in turn required that previous experiences were balanced carefully against the desire to change and challenge the lack of well-being caused by the diseases. This agreed well with the findings from Kralik et al. (2004) where people learned about their responses to diseases through the experiences and as a result of trial and error. They learned about their personal limitations or boundaries and could then make decisions how they should plan and prioritise (Kralik et al. 2004). In order to experience good health, people with various disabilities need to be able to build and maintain a sense of balance between body, mind and spirit, as well as between their social context and environment (Albrecht and Devlieger 1999). This agreed well with the findings from the present study where the individuals experienced health as a harmony and to be in a balance with the body. The body means a unit of the physical body and soul, as well as the individual’s social life. The individuals experienced that the body could not be shared in various parts - everything was connected. Their experiences agreed well with Merleau-Ponty’s philosophy where the physical and the psychological are described as an interwoven unit, the lived body. The lived body is then in constant interaction with the world (Merleau-Ponty 1945/2004).

In the present study health-promoting self-care as experienced by people living with rheumatic diseases required trust in oneself and belief in one’s own ability to make choices. Backman and Hentinen (2001) have found that high self-esteem was predicting a responsible
self-care behaviour style. Feeling of togetherness, fellowship and being like others were important for the choice of self-care in the present study and two other studies found that the individuals acquired a power of life from people around them (Hwang et al. 2004, Hadert and Rodham 2008). This was also in agreement with Malterud and Hollnagel’s (2004) findings where personal and social resources were essential means for tolerating and managing the burden of diseases.

Previous research has shown the effectiveness of exercise on health for people with RA, but the evidence for other self-care interventions has been absent or weak (Vliet Vlieland 2007). The present study offers new insights about self-care. The meaning of self-care was much more than exercise. Self-care was an internal dialogue within the body, but also an external dialogue with the immediate environment. In order for the individuals to perform self-care, they needed to understand how the restricted body functioned. This understanding required time, willingness, and the ability to wait in an active way until the signals emitted by the body became clearer. Often there is no time in clinical practice to give patients the opportunity to have internal and external dialogues; instead there is often an unspoken requirement on the patient to listen, accept and to do what is recommended (Arborelius 2001). It has been shown that patients with RA wants to be informed and that they express a great need for information about the disease and its treatments (Neame et al. 2005), but they do not always understand the information (Hadert and Rodham 2008). It is important that health-care professionals find ways of checking the level of patients’ understanding and only after that they could support and empower the patients to do self-care (Hadert and Rodham 2008). All these findings can be useful to bring into rheumatology care and our claim is that the new knowledge from the present study can be beneficial to health-care professionals. Unfortunately, there is a great lack of studies about how to take advantage of the individual’s personal and social resources.
CONCLUSION

In the present study the meaning of the phenomenon health-promoting self-care as experienced by people living with rheumatic diseases was that self-care was a way of life, and it meant to be ready at all times to understand and respond to signals from the body. Self-care required dialogues, power struggles and choices. Further studies are needed to find the best way in clinical practice to support patients with rheumatic diseases to do and be able to continue with health-promoting self-care.

COMPETING INTERESTS

The authors declare that they had no competing interests.
REFERENCES


