

The meaning of living with rheumatoid arthritis – a single case study based on one woman's eight-year diary

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Background

Previous studies about experiences with rheumatoid arthritis (RA) often have a biomedical perspective. Few studies have discussed the meaning of living with the phenomenon RA from a single-case investigation. This was an important issue when deciding to analyse and interpret one woman's diary, which covered eight years of living with RA. The aim of this study was to investigate the meaning of living with the phenomenon RA, using one woman's personal diary spanning eight years. The present study is an in-depth case investigation with a phenomenological-hermeneutic design. One woman diagnosed with RA eight years ago and the meaning of living with RA, according to her. A personal periodically written diary was used for this study. The text was analysed using a phenomenological-hermeneutic method inspired by the philosopher Ricoeur. Results. The results are presented in two themes and five subthemes. The theme 'To feel doubt, grief and lost identity' mirror the big challenge it is to live with rheumatoid arthritis for body, soul, identity and social contacts in daily life. This theme emerged from the following subthemes: 'Being sad about constant physical pain and the loss of bodily function', 'Being sad about feelings of constant tiredness', 'Losing identity creates a lack of confidence,' and 'Being sad and disappointed when meeting carers and colleagues face to face.' The theme 'To be good enough' mirrors a long process in which an expression of more confidence becomes visible. This theme emerged from the subtheme 'Enjoying the small things in life'. The meaning of living with RA for a number of years seems to have created feelings of not being good enough and also of losing one's identity. The process of implementing a changed picture of oneself and also of implementing a good self-image seems to be a very long and difficult process for a person living with RA. This is an important issue for care staff working with RA patients to be aware of, since it has influence on the RA patient's self-respect.

Key words

Chronic illness, phenomenological-hermeneutic, rheumatoid arthritis, single case study

Tidsskrift for Sygeplejeforskning 3/2009

Introduction

In the Swedish population, inflammatory diseases in joints are common and approximately one million people have been diagnosed with rheumatoid arthritis (RA). The prevalence in western countries is estimated to be one percent among adults, and two-thirds of that number are females [1]. RA is a chronic, progressive, autoimmune inflammatory disease, which means that the body's own immune defence reacts against its own tissues [2]. Inflammations may occur in different parts of the body, but also in the blood vessels, even if rheumatic diseases often are associated with the body. It is important to pay attention to symptoms. If the disease is not treated, it can lead to needless suffering and can cause damage to organs or the skeleton, depending on the type of rheumatic disease. Symptoms such as pain, fever, fatigue, reduced appetite with weight loss, and disability are common. The symptoms are unpredictable and may differ due to which rheumatism it is e.g.

psoriasis arthritis or RA, but for the individuals, it can be a traumatic experience physically, psychologically, socially, and existentially and can cause unimaginable suffering and disability [3, 4].

Background

The International Classification of Functioning (ICF) defines disability as a complex and multidimensional phenomenon, where disability is an "umbrella term for impairments, activity limitations and restrictions on participation" [1] p2. Functioning has been shown to be an important aspect of RA [5], not only physical functioning but also the deterioration of social and psychological functioning [4]. The situation for individuals affected by a chronic disease is often changed in a negative way; their whole life situations often are associated with cognitive, affective, behavioural and physical changes. The Shifting Perspectives Model of Chronic Illness [6] refers to living

with a chronic disease, and this involves constantly shifting perspectives in which either illness or wellness is in the foreground. This can be difficult to live with.

Several people with chronic diseases experience reduced social contacts, social isolation and a feeling of being a burden to family and friends [7]. Also, the diseases influence both family members and other people [8-10]. Support from family/friends and health care personnel are valuable, but sometimes they overestimate pain severity and characteristics and underestimate the negative effects of RA in the person's life, and physicians tend to underestimate these effects as well [9]. Having a good relationship with health professionals has a significant role in the degree of satisfaction [11]. Some RA patients feel that rheumatology staffs are experts in their area, while RA patients regard themselves as experts on their own bodies [12]. The lived experiences of having RA have also shown that individuals relate over time to an increasingly noncompliant body, which means a body that does not behave, as attractiveness and spontaneous movements are gradually displaced by deformity and discomfort. They also experience a body out of synch and a body that draws public attention [4]. Negative socio-economic consequences have been demonstrated among individuals due to work disability soon after being diagnosed with RA [13].

Several studies on living with RA have a biomedical perspective. Few studies demonstrate the existential character of changes and the individual meaning of living with the phenomenon RA from a single case-study perspective [cf. 14]. To study and describe a woman's eight-year diary gives us an understanding of her lived experience of life with RA from an insider's personal perspective, which, according to Thorne and Paterson et al [15], is an important way of studying the phenomenon.

Aim

The aim of this study was to investigate the meaning of living with the phenomenon rheumatoid arthritis (RA), using one woman's eight-year personal diary.

Method

Design of the study

The present study is an in-depth case investigation with a phenomenological-hermeneutic design about one woman who was diagnosed with RA eight years ago. In a case study, the case itself is central and in this case the woman's own written diary is the content of the investigation [16].

Participant

One woman is included in the present study. She is 60 years old and she has suffered from RA for eight years. She is called Karin here, although this is not her real name. Karin is married and has 3 children together with her husband, and they also have 5 grandchildren. She worked part-time

as a nurse's aid at an orthopaedic clinic from 1980-1998, then was on sick leave from 1998-2001, and on disability pension since 2001.

Data collection

The content of the data consisted of the informant's private periodical diary during the years from 1998-2006. In order to examine the meaning of the phenomenon of living with RA, and to achieve an understanding of the subject's lived experiences of the phenomenon [17], the role of the researcher when reading the diary was to reflect on the question of how the informant felt about living with RA.

The phenomenological-hermeneutic approach

The text was analysed with a phenomenological-hermeneutic approach inspired by the philosophy of Ricoeur [18]. The method has been used by others i.e., Sörlie et al. [19], Fagerberg and Kihlgren [20], Haggström [21] and Hounsgaard et al [22]. According to Ricoeur [18], lived experiences will always remain private and therefore it is not possible to express them to another person, although the meaning of the experiences can emerge. When reading the text of the diary it is possible to interpret and explore the meaning of the text itself. The meaning of living with RA disclosed from the diary was interpreted and carried out in a dialogue between the whole and the various parts and between understanding and explanation and between what the text says and what it points to Lindsseth & Norberg [23]. Explanation is a transitional form, from naïve understanding to critical hermeneutic understanding. The method implies that the researcher interprets the written diary text in order to be able to understand the informant's experiences. The first author's pre-understanding stems from her background as a registered nurse and as a researcher in qualitative methods for several years. The second author's pre-understanding stems from her background as a registered nurse working in an orthopaedic clinic and as a researcher in this area.

Analysis

The analysis is carried out in three steps: a naïve reading, a structural analysis and the interpreted whole. First, the text is read several times in a naïve reading, to get a feeling for the whole and the context, and to grasp the essence of the content. In the next step, the aim of the structural analysis is to get an understanding of the diary itself and to validate or falsify the impressions from the naïve reading. The text was divided into meaning units in order to identify parts, patterns and structures that had a meaningful consistency in seeking the explanation of the text. A 'meaning-bearing unit' could, for example, consist of a word, a part of a sentence or even several sentences. The next phase of the structural analysis was to carry out a thorough and detailed analysis of the text. Each 'meaning-bearing unit' was in-

terpreted, reduced and condensed without losing its meaning. The condensed units were then placed in relationship to and interpreted in comparison with each other. Following this, patterns of similarities and differences appeared and were organised into subthemes that dealt with the aim of the study. After that, the subthemes that were connected with each other were placed in relationship to and formulated into two themes. A process of open and critical reading and interpretation of the material was carried out throughout the structure analysis phase. The content of the 'meaning-bearing units,' the condensation, subthemes, and theme were read repeatedly until the final subthemes and theme were established. The second author, who first made an independent analysis, performed a co-assessment. Following this, she discussed the subthemes and themes that the first author had suggested until both authors came to an agreement about what the names and the description should be.

Finally, the interpreted whole entails a new interpretation of the text based on the naïve reading and structural analysis, giving a new understanding of the studied phenomenon.

Ethical considerations

The informant gave her informed consent when asked to participate in the study and was assured confidentiality. She was informed verbally about the purpose of the study, that the material would be confidential, and that she could, at any time, withdraw her participation, without any explanation or consequences to herself. The informant also read the findings and she gave the authors permission to publish it. This procedure is in line with the ethical rules for humanistic-social science research 2007 [24], in Sweden.

Results

Naïve understanding

After several years of living with RA, the illness still affects all parts of Karin's life. The substance of her life has many moments of stress over the course of a long period of time. Karin has to plan her days according to her level of pain; this seems to cause her a lot of daily disappointments and it seems as though she is frightened of accepting her RA diagnosis. The fear also seems to appear in her relation to her family in that she shows a fear of being a burden to her family and at the same time disappointment in not being supported enough. Karin also seems to be very disappointed in her communications with and calls for help to physicians and registered nurses. This might, together with all the other difficulties, be an expression for the fear of losing control over her life. This negatively affects her self-confidence and therefore her strategies for handling the day vary. A small sign of hope and enjoyment in Karin's life appears to be when she is close together with friends who have the same illness.

Structural analysis

The structural analysis created an explanation of the narrated lived experiences of living with RA on a daily basis. From the analysis, two main themes and five subthemes emerged. (Table 1).

Table 1. Subthemes and themes on the meaning of living with RA

Subthemes	Themes
Being sad about constant physical pain and the loss of body function.	To feel doubts, grief and lost identity.
Being sad about feelings of constant tiredness.	
Losing identity creates a lack of confidence.	
Being sad and disappointed when meeting care personnel and workmates face to face.	
Enjoying the small things in life.	To be good enough.

To feel doubts, grief and lost identity

The theme 'To feel doubts, grief and lost identity' mirrors an underlying interpretation embraced from the four subthemes. See Table 1.

Karin expresses in her writing that living with chronic pain seems to be a challenge and daily happen often disappointments. Living with constant pain in her body also seems to affect her mind negatively and a feeling of exhaustion reduces her life quality. In her mind, Karin had a suspicion that she was suffering from RA but the settled diagnosis made it hard for her to accept the pathological picture of herself and this affected her in several ways. Her thoughts about being a burden to her surroundings, including her family, and a fear of becoming dependent on others, and also sadness over invisible, underlying feelings of not getting support and understanding from relatives emerged. The pain seemed to increase over the years and it became more chronic after several years and this was difficult for her to accept and to live with. Living with chronic pain also created a distanced relation to herself and her family. She seemed to refuse to accept and implement the diagnosis in her body versus her mind and living with the disease became almost impossible for her. This also affected her self-confidence in not being able to accept the image of herself as a sick person and not the strong working woman she was before. All this might have had an influence on her lack of confidence and Karin arrived at an isolated way of living where she avoids different social contacts and experiences a lot of daily activities as troublesome and challenging. An internal personal crisis appears. Having to live with a new image of herself creates doubts and grief over her lost identity and this seems still to be the case after nine difficult years.

Being sad about the constant physical pain and the loss of body function

Karin describes how when the pain is at its worst she is not able to do daily activities as she did before. For example, carrying the laundry to the washing machine is a big challenge for her and sometimes she fails and has to ask her husband for help. This makes her sad because she does not like to ask anyone for assistance although her family often offers their help. Sadness seems to be very complicated. She feels anger when her family members do not help her at in the same time she feels anger if they spontaneously offer their help to her. She very often expresses sadness about the constant physical pain and she longs for the life she lived before RA, when she was a strong and healthy woman. Her fingers are becoming more and more stiff and it is difficult for her to use her hands to perform different activities, such as cooking, which is a great interest for her, and also when she is knitting clothes for her grandchildren. She experiences herself as fumbling and she is sad over the increasing loss of her bodily functions, in her back, ankle joints and knees. An invitation to visit friends appears to be a kind of a burden if dancing is a part of the event. Before, she loved dancing but now it is almost impossible to dance and she seems to look at herself as a fumbling and clumsy woman and she expresses difficulties in enjoying such an invitation due to the image she has of herself.

Karin seems to experience a great disappointment in giving up all the things that she was able to do before she got sick with RA. Now she must give up these things due to the pain in her wrists and shoulders and her thoughts about never being able to do these things again creates feelings of sorrow loss, and a picture of her as a weak woman appears.

“...I’ve even had to stop dancing.”

“Knitting is one of my hobbies, but I can’t do it anymore. It hurts my wrists and shoulders too much.”

“Sometimes I feel like a traffic obstacle when I’m crossing the street, because I can’t walk as quickly as I want to, since it hurts my ankles and knees.”

“There are so many things I have to give up when I can’t move the way I want to...”

“Learning to ask for help with things is hard, when you’re used to doing it yourself.”

Being sad about feelings of constant tiredness

Karin expresses in her writing that being tired is a common element of her daily life. Some kinds of tiredness are, according to Karin, easier to understand than others. One reason for the understandable sort of tiredness is when she experiences a bad night. This is caused by pain and difficulties lying comfortably in bed. Almost every night, when Karin tries to sleep she has to move from side to side using the pillow in different ways to get a better position and

more comfort for her pained body while her husband is sleeping. Sometimes this gives her a feeling of loneliness and sadness and she keeps thinking about why this has happened to her. This affects her mind negatively. Sometimes she uses an extra pillow for comfort, instead of human contact. Some mornings, she has to struggle to get up and this causes her to feel tired and it is more difficult for her to understand, especially when the night has been better than usual. In her thoughts, the picture of body pain does not emerge as strongly as the picture of a tired soul. This is not described in words but in a struggle to get up from the bed and to get on with the day. Daily activities such as house-keeping, which always was very important to her, now seem to be a burden to start with. This gives her a new negative picture of herself and it makes her tired. This also seems to affect Karin’s conscience negatively, because she does not do what her mind thinks she ought to do and she gets tired from thinking about it.

In her writing, Karin considers where this tiredness might come from. The physician seems to have encouraged her to think about this question but in her writing there is no answer for this.

“...he asked why I was so tired and you get this way because of all the work you have to do and it feels so heavy...you see the things you ought to do and don’t have the energy, ability, or desire to do...”

“...always tired, I always have pain, and I always have a bad conscience...”

Losing identity creates a lack of confidence

Due to the RA and pain, Karin experiences a loss of identity and a loss of confidence. Before, she seemed to have confidence in herself. At home, she had done everything, including cooking, cleaning, and washing clothes, and at work she was well known as an appreciated and funny workmate. In Karin’s picture of herself, her workmates and friends before looked at her as a woman who always was ready to help them with anything. This identity is now reduced and Karin expresses a lack of confidence due to this. A lot of things she thought were an important part of her personality have become difficult to continue with. She remembered things that she had been able to do before and now she has to ask people in her surroundings for help and this is hard for her to bear. A feeling of lost identity was also shown in that her body took another shape than before and she was, for example, not able to use the shoes she liked; now they have to be specially designed due to the new shape of her feet.

“I am so tired of the pain and tired of my ugly feet and hands.”

“I feel like I get annoyed and irritated or frustrated so easily, I don’t really know which, but I get angry at different things, it doesn’t feel like me. This isn’t how I usually am.”

“...my existence is life living on a staircase with narrow, steep steps, and I stand there and balance, filled with guilt. It doesn't take much to fall down, but it is hard to walk up.”

Being sad and disappointed when meeting care personnel and workmates face to face

Over the years Karin, had to be in contact with different health care staff. When they confirmed that Karin had RA, both sadness and anger came forth. This information was very difficult for her to accept though her mind was prepared for the knowledge that the pain could be caused by RA. In her thoughts about accepting the diagnosis, a feeling of avoidance emerged. Accepting the diagnosis seems to be a great challenge for her and this feeling has not decreased over the years. One main issue Karin had to deal with in her contact with physicians was when she almost was forced to take disability pension. This was a hard time for her and during all the meetings with different care professionals, Karin got more and more suspicious towards the staff. She thought that they had not tried to help her to be able to work again and that they did not listen to and rely on her experiences about living with RA and her chronic pain. Since she got the diagnosis, she has been moved from the orthopaedic clinic to a rheumatic specialist, and from there to primary care and she has also had several operations on her feet and hands. During this time Karin had to deal with a lot of different professionals, which made it difficult for her to get to know, to feel safe with and to trust a special person. She often had to tell the same story several times and she expresses this as tiring and she often felt that the staff were uninterested and sometimes she got a feeling that the physicians did not want to have her there.

Several times she also saw an occupational therapist and she had a feeling that the therapist made Karin seem to be worse than she herself experienced. She began to feel that the staff mistrusted her (did not take her seriously) and her confidence became very low. From the time when Karin was sick and could not work until the time when she had to finish her job at the hospital, she felt that some of her workmates did not take her seriously and she experienced herself as not important any more.

“Was at occupational therapy and tried wrist braces and tried a paraffin bath for my hands. She showed me other aids that are available and are surely good, but I got the impression that she was making me worse than I am.”

“It is the feeling that he isn't talking to you that makes you think he doesn't want you there.”

To be good enough

The theme ‘To be good enough’ mirrors an underlying interpretation embraced from the subtheme ‘Enjoying the small things in life.’ See Table 1.

Although Karin has to struggle in her daily life, as of two years ago, she seems to be a more confident and positive person. The confirmation from others who live in in the same situation seems to encourage her and this helps her to develop and compose a new picture of herself, such that she can adapt this picture and feel that she still is good enough.

Enjoying the small things in life

This subtheme emerged from the last two years of the diary and it mirrors Karin's change to a more positive view of herself. She is now more positive about doing things than before. The difference now is that she allows herself to take the time necessary for doing it. She also enjoys exercise such as walking alone or with a friend and doing water gymnastics. Karin enjoys the possibility getting rehabilitation abroad. Activities that are difficult to do at home are easier to do with good leaders and in a warmer climate. She also feels confirmed by the staff and she feels that they are there for her. At home, she now also experiences a better connection with the professionals. At the same time, her consumption of painkillers has been reduced, and she seems to handle the situation better now. During the rehabilitation sessions, she meets other people who live with chronic pain and with them she feels free to talk about living with RA. Sharing problems with friends in a similar situation seems to create positive feelings, a more positive look on herself and more enjoyment for her future.

“...enjoying myself... get a lot of good training and treatments. My entire self feels good when I am there.”

Discussions and the interpreted whole

The aim of this study was to investigate the meaning of living with the phenomenon rheumatoid arthritis (RA), using one woman's eight-year personal diary. The voice of the diary expresses sadness and grief during all the eight years of writing. The fear of getting the RA diagnosis turns after a while into difficulties accepting the diagnosis and problems coping with mental, physical and social issues. The pain, disappointments with relations and professionals and the fear of becoming a burden made the informant unsure of herself. It seemed to be troublesome to find an identity that was acceptable for her. The writing from the last two years mirrors a small light of joy, where confirmation and association with people in the same situation was important for developing and incorporate a more positive mental picture and this in turn also created a feeling of still being good enough.

In the beginning of the illness, the symptoms create an ascending process in which pain, swelling, and stiffness in different joints are common daily symptoms [3, 4] and this was frightening. The pain controlled the informant's daily life [25] and this seemed to influence life negatively,

from being able to manage most things by herself to being dependent on help and assistance. According to Gustavsson et al. [26], patients with pain can experience shame and doubt due to the reality of always having to feel and think about pain. This happened to the informant and she doubted her own abilities and existence during all the eight years.

Although the informant sometimes experiences a good night of sleep, she can feel constant tiredness, which was difficult for her to understand. This might be a common symptom for people living with RA and according to Power et al. [27] patients often describe the days as being in a shadow without them feeling as though they are truly present. The informant discussed this issue with her physician and he replied by asking why she felt this tiredness. This did not help, but seemed instead to lay a stock of doubt and guilt on herself.

In Åsbring [28] it is shown that women who live with long-term diseases find it very important to associate their identity to employment and most of the women in the studies tried to work at least part-time. Work was not possible for the informant since she was forced to take a disability pension in 2001 and this was one of several reasons why she felt continuous doubts, grief and lost identity. It seems that the grief about lost identity made it difficult for her to compose a new picture of herself and neither the professionals nor her relatives were able to help her forward.

The informant also voiced of sadness when having to look at her deformed hands and feet. She disliked the shoes she had to wear due to the RA and this might be one reason why she avoids some social events. Lost social contacts, feelings of being clumsy and not being the strong and keen woman she was before seemed to be an underlying threat to her identity during the eight years and she was very lonely with this fear. As was also shown in Hwang et al. [29], support from family and others is important and in this case the informant did not receive enough understanding from family, friends and former workmates in her new situation. This affected identity negatively and due to this, she often decided to stay at home and also made considerable efforts when integrating with others [30].

The grief, doubt and lost identity were cumulative during the years. Although the informant met a lot of different professionals they all showed lack of concern. They neglected her expressed needs and she often felt invisible, disappointed and not taken seriously in her meetings with professionals. This expression was also shown in Fair's [31] study where RA patients described disparities in patients' and providers' descriptions of having RA. In this study we felt surprised by still finding these phenomena after all the years. It is difficult to understand why the informant had to feel this and it is also a failure on the part of the professionals in care. Maybe the professionals can

see the RA women's suffering but they avoid seeing them because it is too hard to meet each individual's problems in daily life. If this is the point, care professionals need more education about seeing and meeting RA patients. Related to this, it might also be difficult for friends and relatives to deal with the suffering from RA patients and it can be a reason why confirmation and understanding from them often not did occur for her. In this study it seemed like confirmation from others was the most important point for the start of developing and incorporating a more positive picture in informant's mind. Maybe the time has come when professionals, friends and relatives have to be trained both separately and also together to get more security in working with RA patients. According to the diary, the informant was left alone and also her family was left alone. It is a big trauma for the whole family to be affected by RA [32] and we think that professionals, friends and relatives can learn a lot from meeting RA unions together in several ways. The reason for this statement is the informant's expression, after seven years of writing in the diary, of being confirmed and feeling a little hope and joy together with men and women in a similar situation and with similar diseases [33]. This is an important issue when studying the phenomenon of living with RA. It might help and be easier for professionals, friends and relatives to confirm and help the RA woman's long process to reevaluate her identity positively and help so she does not feel trapped.

Methodological considerations

A phenomenological-hermeneutic method was used for this study. Usually, narrative interviews would be used, but in this study, the researchers chose to use a diary periodically written over eight years. This was done to get insight into the deeper meaning of living with RA for several years. According to Ricoeur [18], the starting point for the analysis is the written text. Since the text is written down, the informant is considered dead and when the text is analysed, it is the researcher's interpretation that is emphasised. In this study, the meaning of living with RA for eight years was analysed. This interpretation is one of several possible interpretations that should be seen in relationship to the deeper meaning of living with RA for a long time. The informant wrote short but expressive pictures of her daily life throughout the eight years, and this strengthens the study's trustworthiness by getting a deep continuous interpretation [34]. To increase the credibility of the analyses, a careful description of the method is done. According to Ricoeur [18], the interpretation allows you to be touched by the text and the interpretation is the authors' interpretation. In this single case study, which took place over eight years, we were touched by the text and the long time studying the phenomenon might be a reason for transferring the findings to another context.

Conclusions

The meaning of living with RA for a number of years seems in this case to have created feelings of not being good enough and also of losing one's identity. For example, the informant lost her self-image that incorporated the person as a whole. Although this negative picture was dominated the informant felt more meaning in life after some years by adapting a new picture of still being good enough. To work with patients living with RA and their relatives, one point of the treatment has to be continuous support in regard to helping them to incorporate a good picture both for the person living with the disease and also the relatives, since they influence the RA patient's self-respect. This has to be done in a continuous and developing process in a team with the patient, professionals, relatives and other people living in the same situation.

The process of implementing a changed picture of oneself and also implementing a good self-image seems to be a very long and difficult task for a person living with RA.

Contributions

Study design: EH, AN; analysis: EH, AN; manuscript preparation: EH, AN.

Acknowledgement

The authors wish to express their gratitude to the woman who was willing to share her experiences of living with RA by letting us read and interpret her diary.

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