

Like the worst toothache you've had - How people with rheumatoid arthritis describe and manage pain

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ABSTRACT

Title: 'Like the worst toothache you've had' – how people with rheumatoid arthritis describe and manage pain

Background: Rheumatoid arthritis (RA) is a chronic inflammatory disease often associated with disability. Despite new treatments, pain and activity limitations are still present.

Objectives: To describe how persons with RA experience and manage pain in their daily life.

Methods: Seven semi-structured focus groups were conducted and analysed using content analysis.

Results: The analysis revealed four categories: 1) *Pain expresses itself in different ways* referred to pain as overwhelming, aching or as a feeling of stiffness. 2) *Mitigating pain* referred to the use of heat, cold, medications, and activities as distractions from the pain. 3) *Adapting to pain* referred to strategies employed as coping mechanisms for the pain, e.g., planning and adjustment of daily activities, and use of assistive devices. 4) *Pain in a social context* referred to the participants' social environment as being both supportive and uncomprehending, the latter causing patients to hide their pain.

Conclusions: Pain in RA is experienced in different ways. This emphasizes the multiprofessional team to address this spectrum of experiences and to find pain management directed to the individual experience that also include the person's social environment.

KEYWORDS: activities, adapting to pain, mitigating pain, social environment

INTRODUCTION

Rheumatoid arthritis (RA) is a chronic inflammatory disease often associated with disability (1, 2). The incidence of RA in Sweden is 41/100,000 (3) and more women than men are affected (1, 4). The treatment strategies for RA have been dramatically reformed during the last 20 years, through early diagnosis, timely use of disease-modifying anti-rheumatic drugs (DMARDs), and the introduction of new and effective “biological agents,” which have all led to reduced disease activity and fewer reported disabilities (5, 6). However, despite these new treatment strategies, disabilities are still reported, which indicates the need for further non-pharmacological multi-professional interventions to complement the medication (7-12).

The majority of patients with early diagnosed RA report their pain to be high to moderate (13) and it is predominantly reported that pain reduction is a high priority symptom to reduce (14, 15). Traditionally in RA, as well as in other chronic pain conditions, pain, is reported in terms of intensity on a Visual Analogue Scale (VAS) in mm (16). However, pain intensity is only one singular dimension that can be assessed and described when investigating a person's experience of pain. Pain is a multi-factorial, complex phenomenon that needs to be assessed from a multidimensional perspective (13). The bio-psychosocial model (17) identifies pain as the result of the dynamic interaction between physiological, psychological and social factors in the experience of a disease such as RA. Furthermore, the definition of pain by the International Association for the Study of Pain (IASP), as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” (18) gives legitimacy to the unique experience of each person suffering from pain. Therefore, a person's description of their pain cannot be questioned.

Pain in RA is strongly associated with activity limitations in daily life (8) and less related to

disease activity (13). Due to their pain, those with RA tend to perform fewer household, leisure and work activities (19). Persons with RA have to change or adapt activities (8) leading to big alterations in the person's life (1). Sinclair and Blackburn (12) reported that to manage RA pain, the acceptance of change in roles and activity patterns and also re-prioritization of values is required. However, activities have also been described as a way to distract oneself from the pain (8).

In order to increase multi-professional rehabilitative interventions directed at reducing pain and activity limitation, patients' description of pain, as well as strategies for pain management in daily activities are required.

AIM

The aim of this research is to gain insight into how people with RA describe and manage the complexity of pain in their daily life.

MATERIAL AND METHODS

Design

This study employed a qualitative approach and material was gathered through semi-structured focus group interviews (20, 21). Focus group interviews provide opportunities of social interaction, discussions and possibilities to express individual thoughts in a group to capture a complex phenomenon (21) as pain in RA. Data was analyzed through qualitative content analysis, with a manifest focus, meaning dealing with visible and clear components, rather than interpreting (22).

Participants

Recruitment was carried out in cooperation with three Rheumatology Units in Sweden (8). Inclusion criteria consisted of: a diagnosis of RA for at least four years and a reported pain intensity of >40 mm (using the VAS) in their two more recent clinical visits. Co-morbid pain or cognitive impairments and limited Swedish language fluency were exclusion criteria. Participants were initially recruited using purposive sampling, based on data from the Swedish Rheumatology Register (SRQ). Following this, stratified sampling (23) was employed to select potential participants based on age and gender. The rationale for this procedure was to cover possible variation in data, further described in Table 1. From the 77 RA patients who were identified and invited to participate, 33 accepted, after which the seven focus groups were carried out. An overview of the seven focus groups is shown in Table 1. The focus groups were homogeneously formed in consideration of gender and age.

-----Insert Table 1-----

Procedures

The focus group interviews were semi-structured and based upon a pre-defined interview guide (24), which was specifically developed for the target population and included questions about descriptions of RA pain and the consequences of this pain in daily life. The focus group discussions (FGs) had one assistant who recorded the discussion in note form, and one moderator. The moderator's role was to lead the discussion and create an atmosphere that allowed the participants to express their personal and shared experiences of the phenomena. Upon conclusion of the FGs, the assistant validated the findings by summarising the discussion for the participants and asking for confirmation and / or if clarification where required (25). The FGs were audio recorded and transcribed verbatim.

Data analysis

Data were analysed using qualitative content analysis (22). Meaning units were identified, condensed, abstracted and coded into categories and sub-categories by the first author (MBe). The categories and sub-categories were then reviewed by two moderators (i.e., the second author (IA) who was present during all the FGs, as well as a patient research partner who was educated in research methodology by the Swedish Rheumatism Association), in order to ensure maximum confirmability (23). Following this review two more sub-categories were identified and the names of the categories and sub-categories were further clarified.

Examples, step by step from meaning unit to category are presented in Table 2.

Representative quotations were identified from the transcribed text to facilitate the credibility of the findings (22).

-----Insert Table 2-----

Ethical considerations

The study was approved by The Regional Ethical Committee at Linköping University Dnr 2010/42-31.

RESULTS

Four categories with 14 underlying sub-categories (Table 3) were identified through the focus group discussions. Letters and numbers presented together with quotations correspond to the information presented in Table 1 (e.g., a quotation taken from focus group 1 is presented FG 1).

-----Insert Table 3-----

Pain expresses itself in different ways

Although the participants clearly stated that pain is difficult to describe, it was often mentioned as a roller coaster, i.e., going up and down, sometimes very fast and moving from body part to body part.

Overwhelming pain

Pain was described as strong, intensive or explosive and unbearable, with a cutting, pinching or burning sensation. Since many of the participants also found it hard to describe pain, they had come up with different ways to explain the sharp sensation, to make it easier for others to understand it, such as: "a graze on your knee...the burning." (FG 7). The concept of pain was described as something that for a completely healthy person would be short and intense, but for RA patients, the pain was intense for a longer period. Expressions were used to describe the pain, such as, having poison in your body or your joint boiling. One participant compared the pain to being shot: "I don't know what to call it, getting shot by a canon or something." (FG 1). The sudden onset of pain was described as a bolt of lightning hitting the hand and the abrupt pinch of pain could instantly make movement impossible. The intensity and the feeling of helplessness become so extreme that the RA patient would not know what to do or how to cope. One participant described how she would simply sit in her bed at night screaming and crying from the pain, particularly when she felt that there was nothing she could do about it. Some participants expressed a wish to remove the body part in pain. One participant mentioned the uneasiness of feeling that way, when the pain got that intense: "It's a very scary, nasty pain I think. When it gets that way, you feel like you just want to take the arm off, you just want to get rid of it. It's really scary." (FG 6).

Aching

The participants distinguished between an intensive sensation, and aching, with aching being described as more dull. It was explained as more tender and in some cases, more concentrated, specifically to the joints. One participant described it as like being tied down and trying to break free. Similarly, a general sense of feeling something heavy or strenuous was mentioned. The aching type of pain was the kind that would keep you up at night, as well as slow you down. In some cases, it was described as a type of cramp. Comparisons were made with a sprained ankle, and a very common comparison was: “like the worst toothache you've had.” (FG 6). For some it was tricky to find good sleeping positions during the night, since the aching could decrease for a few minutes but then get worse again, forcing you to shift position once again. This result was inconsistent however, as one participant expressed how she never felt any sort of pain while sleeping.

Pain as stiffness

Pain was also described as stiffness, which was expressed as problems with moving around, muscles that felt shorter than normal, and hands that felt like they were being put in boxing gloves and were unable to grip. Stiffness could occur exclusively in joints or all over the body at once. The type of pain that was perceived as stiffness was in some cases more frequent in the morning. Inability to bend legs or fingers, due to the pain and stiffness was also mentioned: “My pain is also perceived as stiffness, I mean stiffness in the joints. And then it's stiff. And then I can't bend my fingers or knees or anything like that.” (FG 2).

Does it show?

Many of the participants mentioned that pain was something that is on the inside and therefore does not show. However, it was also discussed that you can tell that someone is in

pain from how they walk, or how they move their wrists and fingers. Someone mentioned that it was easier for people to see the pain if you have to limp, but as one participant explained: “They can't see that I have RA just because I'm in pain or limp.” (FG 7). This was suggestive that although the pain itself was visible, the reason behind the pain was not. The first and most common people to notice the pain were the closest family members, such as a spouse and children. Mostly they were able to see the pain from the mood of the participant. It was discussed that pain also had a dynamic relationship with fatigue and stress, specifically that being tired was another way the pain could be visible to others.

Mitigating pain

The participants described several strategies to ease the pain, even if they couldn't make the pain go away entirely.

Temperature and climate

There was a widely spread use of temperature to ease the pain although results were inconsistent. One participant explained that “Cold or heat, anything in between is useless.” (FG 2). Strategies using heat were used more frequently than those using cold, for example: hot baths, saunas or heated pillows, and warmer weather. Several participants mentioned things they could perform much better in warmer climates, such as walking up stairs: “...it was between 35 and 40 degrees [Celsius] the whole time, but it was a dry heat. It worked perfectly and I felt like a prince. I have never walked so many stairs as I did down there.” (FG 1). However, some differences between participants were reported: “-I like the heat. - Yes, me too. -Well, I almost feel worse when it's warm” (FG 5). In contrast, some participants felt that using cold methodologies as a way of easing pain, were more effective for pain management than heat. For example, one participant described the relief she felt when going

out on the balcony during the winter as it would cool the swelling in her feet. In general cold tended to be used more frequently in an acute situation or to promote swelling reduction. “If it's really painful, or throbbing, then you use ice on it.” (FG 6). However, another participant mentioned that she felt worse while trying to use ice for the pain.

Medication

When given medication, for example corticosteroids, feelings of joy and pain relief were expressed. In one case, the medication made the participant completely symptom free. Using biological treatment to ease the pain was often expressed as something essential in order to achieve basic daily functioning. It was described as a rapid method for pain relief, as well as something to use if nothing else worked: “But that kind of pain I have been in, that kind of condition I have been in, there hasn't been any other alternative.” (FG 3).

Activities as distraction from pain

The use of hands in activities was reported as a positive distraction from pain, such as baking, knitting and painting, as well as the use of other physical activities such as, water aerobics, Qi-gong or going for a walk: “Yes, and it [water aerobics] is completely wonderful. The pain kind of, well it kind of disappears.” (FG 3). Other methods of distraction were interacting with friends, family, work colleagues or pets. A purring cat in one's lap was described as providing comfortable vibrations for the hands.

The use of alcohol was also mentioned as an effective method for easing pain. Several participants mentioned that a glass of wine both could ease the pain and improve mood. However, some participants reported being more cautious as they had found themselves suffer greater pain after drinking alcohol. The risk of alcohol addiction and dependence was

also discussed: “-Because it's really effective and there is a risk... -You get stuck with it. -You use it a bit too much.” (FG 4).

Adapting to pain

In order to manage pain, the participants also mentioned different adaptation strategies.

Learning to live with the pain

There were discussions about the need to get used to and live with the pain. For many it was considered important to continue with life as much as possible: “It can't take over my entire life.” (FG 3). There was also discussion about how participants felt they had learned to be more careful in performing activities, sometimes automatically, as a way of adapting to the pain: “You kind of fend off [the activities] without thinking about it after a while.” (FG 4). Not all the participants had accepted the pain completely and some thought that they might never do so, however it was mentioned by some, that if you came to terms with it, it could be considered easier to live with.

It's essential to plan activities and daily life

The need for different kinds of planning activities was essential, although it was also made clear that planning is not always easy, as it is usually not possible to know from one day to another how bad the pain will be. “But you can't say you can come tomorrow, I can have a little dinner party, because I have to check first that morning, if I can handle this.” (FG 5). The planning itself was described as a way of adapting activities in order to manage the pain, e.g., thinking about what kind of clothes to buy, as buttons were not always the best choice: “You pick your clothes and shoes depending on the pain you're in that morning.” (FG 7). It was also important to think before acting, for example not sit or lay down if the participant

was uncertain if the pain would stop them from getting up again: “But I can also crawl in [to the bath tub] but it's like you say, you have to check beforehand, do I think that I can get up or do I lay here until I'm a raisin.” (FG 7). Another example was to think about were to sit in a larger crowd: “I'm not jumping right into the middle in a kind of big cinema or something, and sit there and it hurts like hell for two hours, but then I want to sit on the edge.” (FG 7). Some participants were also planning for the future in the sense that they were thinking about moving to get rid of a big garden or stairs in their home.

Giving up activities

One way of adapting activities to mediate the pain was by no longer performing or taking part in specific activities. Due to the sacrifice of these activities, several participants would experience sadness and disappointment, especially when it came to interacting with grandchildren: “What hurts the most, what I cannot do. It's my new small grandchildren... I can't play with them. I can't get down on the floor.” (FG 1). Gardening, carpentry, knitting, driving, exercising and travel were examples of activities that the participants took part in less frequently, or had stopped performing completely because of the pain. Social occasions could be problematic, sometimes because of the planned activities or the dressing requirements. Participants also reported problems with taking trips due to long travel times and the need to sleep in an unfamiliar bed. Drinking alcohol in restaurants or at dinner parties was also something several participants chose not to do, in attempt to mediate any increase in future pain.

Devices and gadgets

Several different types of gadgets were found to be helpful in the process of adapting to the pain. These included prescribed or adaptive equipment such as a crutch, orthoses or a walker,

but also individualized solutions that exist in the environment, such as a car with an automatic gearbox or the self-scanning system in supermarkets. Good walking shoes and orthopaedic shoes were reported to have a positive impact: “It reduces the pain a lot. You don't think that a couple of slippers can do that, but it's absolutely unbelievable.” (FG 7). Ergonomically developed pillows, kitchen equipment or office supplies also helped with adapting to the pain. The comment: “I have had an air mouse for many years, otherwise I would never be able to sit in an office” (FG 2), shows that devices can be a condition for being able to do your work despite the pain. One participant also mentioned the importance of her work space being ergonomically adapted with a specialized chair and a desk that is height adjustable.

Pain in a social context

The social environment had both a positive and negative impact on the participants' lives. It provided ways to improve pain management however, it could also provide obstacles to pain management.

Support from the social environment

To be able to manage pain, the ideal was to surround oneself with people who could offer support. Significant others in the participants' lives were primarily a partner or spouse however, they could also be close friends and family. In addition, understanding colleagues and effective treatment from the health care system were considered sources of support. “It is like that, you get more energy if you get the right conditions. Then it gets better and it favours the job.” (FG 7). It was important for the participants to feel that they could contribute despite the pain, and therefore it helped if the partner, or other sources of support, were understanding. “I get to point [things out] and then I feel like I'm involved as well....

Sometimes I try to clean the windows but he's the one who has to do most of it later, and make the bed and clean.” (FG 3).

Lack of understanding from the social environment

The feeling of loneliness and the sense that friends had stopped involving them, were examples of the negative impact that the social environment could have on pain management.

It was a hurtful and disappointing feeling when friends or employers would pretend and act like the pain did not exist. Two main concerns were that people would not take the pain seriously, and participants would find they were constantly listening to others saying that it was not possible to tell that the person was ill or in pain, sometimes because the person simply seemed too happy to be in pain. “But you can't tell... What should I do, should I walk like this just to show how much it hurts? I mean, it can be really frustrating sometimes. And everyone doesn't see that you maybe eat four painkillers a day, or even more” (FG 7).

Participants were also concerned that those around them would think that they were just whining: “Then they think that you've got this imaginary disease. Me and all my diseases, you know.” (FG 5).

Hiding the pain

Many different reasons for hiding the pain were discussed. One participant reported that they did not want to make a bad first impression at a new workplace, and another participant reported that they kept quiet because their partner got really nervous if there was any talk about pain. Examples of trying to make jokes about it or feeling embarrassed about the own body, were also reported: “But then you put on a mask maybe if you're going out to do some stuff.” (FG 6). It was also commonly reported that pain was hidden when in certain company e.g., in front of older people, children or grandchildren. The participants reported that they

did not want to be someone's burden, and in some cases the reason for hiding the pain was also to not get overwhelmed with advice for cures.

DISCUSSION

The main results of this study are that pain in RA can express itself in several different ways, such as a strong and overwhelming feeling, aching or stiffness. Furthermore, in order to manage pain, the participants' stated that it is important to have different strategies to ease the pain and to adapt to the pain. A social environment can be supportive in order to manage pain, but can also to have the opposite effect.

The participants found pain difficult to describe. The fact that pain is difficult to describe is mentioned by other studies in investigating RA (26-28). Pain has earlier been described as "boiling", "tender", "agony" (27), "burning", "stiff", "attacking" (26), "sharp" and "aching" (28). Although, when the participants of the study by Hewlett et al (26) talked about stiffness, it was described as more of a symptom of RA, rather than pain, whereas the participants of the current study used stiffness to describe the pain itself. The participants' expression of the desire to cut off aching body parts has also been previously identified (26, 27). A similar wish has been described as to "crawl out of your own skin and just leave it" (28). Our study contributes to the fact that pain is a unique perception and that strong words are used to describe it.

Medication is found to be the most common strategy for coping with pain (29), and is seen as an integral part of daily life (30). The present study included participants with established as well as early RA, consequently diagnosed both before and after the introduction of biological medications with different conditions of early intense treatment. Nevertheless, at time of the

focus group interviews, the biological medications had been introduced and used by participants, both with early and established RA. The use of biological agents to manage pain has previously been reported (10, 26, 28, 31, 32), as well as adults with RA reporting that pain symptoms would disappear entirely from the usage of medication (10, 30). Although, other studies report conflicting attitudes towards medication (10, 28), the participants of the current study presented an overall positive report for the use of biological treatments for the management of pain. Although, the participants of the current study did express that the process of finding the right medication could be long and painful, which adds to the importance of looking at other ways to ease pain but through biological therapy.

The use of temperature, i.e., hot and cold, (26, 28, 30) and adapting regular activities were found to be important strategies for adapting to pain, which is in accordance with earlier research findings (8, 26, 28, 29, 33, 34). Different forms of physical activity were reported as a distraction from the pain, although to a smaller extent than earlier studies (29, 32, 35) and mainly referred to water aerobics. Interacting with pets was reported as a prominent pain distraction. This was reportedly due to the activity with the pet being both soothing and that there was little preparation required for the activity as the animal will not judge its owner's appearance. Since individual roles and habits are a dynamic part of daily life (36), it is understandable that a situation like that can be a positive experience.

Giving up activities was also a way of managing pain, and to some extent, moderate the associated negative feelings. This corresponds to previous studies, which have mentioned the feeling of loss due to the inability to perform certain activities (31), and the subject of feeling better once the fact that the activity can no longer be undertaken is accepted (33). Changes in activities or giving them up completely can have a big influence on a person's roles and

volition (36). It is therefore of great value to consider, that if a person with RA can accept their disease and limitations, they may feel better as a person, which is stated by participants both in the current study and previous ones (33).

Social support was reported as a very important facilitator when managing pain, which is in accordance with earlier findings (28, 32, 33, 34). Similarly, a lack of social support has shown to have a negative impact on living with pain, both in the current and previous studies (32, 34). Other studies report problems with disbelief from the health care system (28), whereas the participants of the current study reported positive impression of the health care system and felt that they had an appropriate amount of support. To have a positive interaction with others should therefore be considered of importance to manage pain.

As with the findings of the current study, other authors have previously noted the wish to hide the pain among people with RA (31, 32). Those with RA still want to be seen as normal or in the same way as in previous encounters. Even though a person can have a number of different roles, a disease like RA can change one or several of them, meaning that the dynamics around a person would be unbalanced (36). If this situation occurs, a supportive social environment is therefore of utmost importance, which is highlighted by the current study.

Methodological considerations

Qualitative method aims to explore phenomena, peoples' experiences, and the complexity of human life (23), which is what this study intended to do. The use of homogeneous focus groups with regard to age and gender is recommended, since the participants then can feel that they have more similarities with people in the same situation (21). However, the results may not be generalized to a larger population in qualitative studies (20).

The ability to use the Swedish Rheumatology Register (SRQ) and the inclusion criteria with pain intensity > 40mm (16) the last two clinical visits strengthens the sampling method. The reason for drop-out in our study was insufficient time availability in potential participants, but also inability to handle extra additions to daily life due to high levels of pain. However, those who chose not to participate were found in both sides of the spectrum, which should limit the impact it may have had on the results. The credibility of results was facilitated in this study by member check, as the opportunity was given to each participant to add or clarify points at the end of each focus group (22). Credibility was also improved by presence of an experienced moderator in all focus groups (23) as well as, having the peer-review process include the moderator and experienced research partner.

Clinical implications,

Even though both the current study and previous studies have found DMARDs, including biological agents, to be of great importance to people living with pain, it is also worth noting that in isolation, these medications are not enough to wholly manage pain (10, 11, 28, 37).

The results from this study give the participants' point of view when it comes to describing and managing pain after introduction of biological medications. In addition, they have described the importance of their social environment, and expressed what kind of behaviour is desirable in order to support them, and what kind of behaviour is not. This information will be useful to all health care professionals, as it will assist with making a holistic assessment of the patient's situation and will enable the provision of appropriate advice and treatment. The information outlined as part of this research will also be of use to the families and social support of those with RA as it helps to further understand the complexity of the condition.

Conclusion

People with RA express pain in different ways. This emphasizes the multiprofessional team to address this spectrum of experiences and to find the pain management directed to the individual experiences including varying temperature, medication or distractions through activities, and adapting to the pain through learning to live with it, planning, using assistive devices and / or by activity cessation. As this study clearly shows that the social environment is highly influential, it is something that should always be considered in pain management.

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Conflicts of interests

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Table 1: Overview of participants in the seven focus groups (FG's).

FG no.	No. of participants	Age (range)	Gender
1	4	68-73	Men
2	6	50-63	Women
3	4	66-68	Women
4	3	59-62	Men
5	5	68-71	Women
6	7	50-65	Women
7	4	34-37	Women

Table 2: Examples of meaning units, condensed meaning units, codes, sub-categories and categories.

Meaning units	Condensed meaning units	Codes	Sub-categories	Categories
It stings, I think. It can sting like, like a thousand needles but even worse.	Stings like needles but worse.	Pain is stinging	Overwhelming pain	<i>Pain expresses itself in different ways</i>
I don't think that living with the pain is that hard, because you get used to it.	Living with the pain is not hard if you get used to it.	Getting used to the pain	Learning to live with the pain	<i>Adapting to pain</i>

Table 3: Categories and sub-categories found in respect to how people with RA describe and manage their pain.

Categories	Sub-categories
<i>Pain expresses itself in different ways</i>	Overwhelming pain
	Aching
	Pain as stiffness
	Does it show?
<i>Mitigating pain</i>	Temperature and climate
	Medication
	Activities as distraction from pain
<i>Adapting to pain</i>	Learning to live with the pain
	It's essential to plan activities and daily life
	Giving up activities
	Devices and gadgets
<i>Pain in a social context</i>	Support from the social environment
	Lack of understanding from the social environment
	Hiding the pain