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RESEARCH PAPER



## Significant others' influence on participation in everyday life – the perspectives of persons with early diagnosed rheumatoid arthritis

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### ABSTRACT

**Purpose:** To describe the meaning of significant others in relation to participation in everyday life of persons with early diagnosed rheumatoid arthritis (RA).

**Materials and methods:** Fifty-nine persons participated in this interview study. Inclusion criteria were three years' experience of diagnosis and being of working age. Semi-structured interviews were conducted using critical incident technique (CIT), and the material was analysed using content analysis.

**Results:** Four categories were revealed: (1) *My early RA causes activity adaptations for us all*, referring to the person and significant others modifying activities. (2) *Making the significant others balance between shortfalls and participation*, where the participants distinguished between needing help and feeling involved in activities. (3) *Physical interactions with significant others*, referring to both the problematic and manageable impact RA could have on body contact. (4) *Emotions in relation to activities with others*, where participants described feelings of failing others, and anxiety about future activities.

**Conclusions:** For persons with early diagnosed RA, significant others can be both hindering and facilitating for participation in everyday life. As a clinical implication, it is valuable to identify how significant others can be involved in the rehabilitation process, to enhance participation in everyday life early in the disease process.

### ARTICLE HISTORY

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### KEYWORDS

Activity; disability; everyday life; interaction; qualitative; social environment

### ► IMPLICATIONS FOR REHABILITATION

- Significant others of persons with rheumatoid arthritis can facilitate as well as hinder participation in everyday life, even early in the disease process.
- It is important to include the significant others in the rehabilitation process of persons with early diagnosed rheumatoid arthritis.
- It is of great importance to identify when and how significant others can be facilitators of participation in everyday life for persons with early rheumatoid arthritis.
- To make it easier for significant others to facilitate participation, there is a need for the healthcare system to explore ways to support significant others with easily accessible information about early rheumatoid arthritis.

## Introduction

Participation restrictions are well known and reported in regard to established rheumatoid arthritis (RA) and regarding different aspects of everyday life [1–4]. During the last decade, the introduction of new biological treatments has lowered the disease activity [5] and new routines have been introduced for RA [6]. Despite this, disabilities and participation restrictions are still evident in persons with early diagnosed RA [7–9]. These cause feelings such as grief, sadness, exclusion, and shame, and persons with early RA can feel hindered in a social context with significant

others [10]. In early RA, participation restrictions have recently also been reported by Benka et al. [11] to be related to increased pain and fatigue in everyday life. Participation is a central and important concept in rehabilitation, and research shows that participation in meaningful activities has a positive influence on health and well-being [12].

In established RA, the social environment, including significant others, has been valued as essential, for example regarding pain management [13] and participation in daily activities [2–3]. However, Kostova et al. [3] report that among persons with

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established RA, only a few experience support from their significant other, and this lack of support affects their everyday life in a negative way. In this study, a “significant other” refers to someone the person considers important and close. It is often, but does not have to be, a blood relative or a close family member. The term has previously been used in research considering social interactions, and illustrates the importance of the person, rather than the family relationship [3,7].

There is a lack of studies on significant others related to persons with RA and participation in everyday life. In addition, the existing research in the area of persons with RA and participation focuses mainly on established RA. However, symptoms have been reported to have a greater impact on everyday life in the earlier stages after diagnosis, and the need for a supportive social environment is also greater during this time [14,15]. Therefore, increased knowledge about participation and how it can be enhanced and supported by the social environment is called for when it comes to persons with early RA. The aim of this study is, therefore, to describe the meaning of significant others in relation to participation in everyday life of persons with early diagnosed and contemporary treated RA.

## Materials and methods

This interview study is part of the multicenter project TIRA Early Interventions in RA (TIRA) [16]. Persons that were included in this early RA cohort fulfilled at least four of the seven 1987 American College of Rheumatology classification criteria (ACR-87) [17], or had morning stiffness  $\geq 60$  min and symmetrical arthritis of the small joints, or had positive Anti-CCP and at least one peripheral joint with synovitis. All included participants were also clinically diagnosed. The diagnosis of early RA was based on international standard of  $\leq 12$  months' disease duration at the time of inclusion in the TIRA project. There were no exclusion criteria and the participants were included consecutively. A total of 522 persons were included in the TIRA cohort at their time of diagnosis between 2006 and 2009.

## Participants

The inclusion criteria for this study were having three years of experience of RA after diagnosis and being of working age ( $< 64$  years of age). In 2006, 128 persons were included in the TIRA cohort, and in order to include participants with three years of experience after diagnosis, recruitment of participants for this study started in 2009. The 59 persons, who were under 64 years of age at the time of inclusion in the TIRA cohort, were informed about the aim of the interview study, that their participation would be voluntary, and that they could withdraw at any time without it affecting their medical treatment. Eleven persons (eight women and three men) declined, leaving 48 participants. To increase the number of men in the study, 15 men in the cohort who reached three years post-diagnosis in 2010 were subsequently invited. Four of these men declined, leaving 59 participants in this study (Table 1). The participants are interviewed persons with RA, sharing their views on the meaning of their significant others in relation to participation in everyday life. The significant others themselves have not been interviewed and are not included in the term “participants” in this study.

## Data collection

Prior to the interviews, the questions were pilot-tested on five patients with RA. After the pilot testing, minor changes in the interview questions were made. The participants chose the location for the interview: their home, workplace, at the hospital, or at the university. The interviews were performed by three of the authors – two social workers (AS, GÖ) and one occupational therapist (EV) – none of whom was involved in the clinical care of the participants. The interviews were conducted using the critical incident technique (CIT) [18], they were semi-structured and featured open-ended questions about participation restrictions related to RA in everyday life. CIT has previously been used in studies on patients with different diagnoses [19–21] and is a flexible data collection method where problematic situations, referred to as incidents or dilemmas, experienced by the person being interviewed, are explored by the interviewer [18]. The interview questions were shaped according to the chosen method, and aimed to capture close at hand critical events in the participants' lives. The interviews started with questions like: How is your everyday life? Can you describe a situation, preferably during the past week, when you were hindered by or reminded of your RA? Follow-up questions encouraged the participant to describe the situation in more detail, e.g., what happened in the situation and what feelings and thoughts were experienced. The interview guide also included questions about the effect RA might have on interaction with others, giving the participants the possibility to describe such situations in detail. Only the persons with RA were interviewed, and it is, therefore, their views that are presented in the results of this study. The interviews lasted between 45 and 90 min, and they were recorded and transcribed verbatim. The data collection period was between October 2009 and May 2010.

## Data analysis

The material was analysed using content analysis. Meaning units found in relation to the aim of this study were condensed into sub-categories and categories, using the steps described by Graneheim and Lundman [22]. The steps involved the transcribed text being divided into meaning units, which consisted of situations where significant others played a role for participation in everyday life, in order to focus on the aim of the study. The meaning units were then condensed and abstracted into codes. The codes were then sorted into sub-categories and categories. The fourth author (EV) performed the steps of dividing and condensing the meaning units from the material. This process was validated by the first author (MBe). At this point, meaning units were added, condensed, and abstracted into codes by the first author (MBe), a process that was validated by the coauthors. The first author (MBe) continued by abstracting the condensed meaning units into codes, and sorting them into sub-categories and categories. To increase credibility [22], the categories and sub-categories were checked by three of the coauthors who individually sorted a number of meaning units into categories. This resulted in a close match among the authors in 85% of the meaning units, and a complete match in 53% of the meaning units. After discussions, full consensus was reached. Examples of the steps in the analysis, from finding meaning units, to deciding categories, are presented in Table 2.

## Ethical approval

The study was approved by The Regional Ethics Committee at Linköping University, Dnr M168–05 T84–09. The participants gave their written consent to participate in the study.

Table 1. Sample of persons with early rheumatoid arthritis taking part in the data collection 2009–2010.

Participant no.	Gender	Age	Civil status	Type of employment	Employment (%)	Education level
1	Female	63	Single	Nurse	100	Higher education
2	Male	58	Single	Industrial worker	100	Primary
3	Female	57	Single	Kitchen assistant	50	Primary
4	Male	63	Married	Technical support	100	Secondary
5	Female	53	Married	Pharmacist	100	Higher education
6	Female	53	Cohabiting	Social worker	75	Higher education
7	Female	52	Couple living apart	Work inspector	50	Higher education
8	Female	55	Single	Job seeker	0	Secondary
9	Female	30	Cohabiting	Social worker	100	Higher education
10	Male	44	Married	Mechanic	100	Secondary
11	Male	47	Single	Industrial worker	100	Secondary
12	Female	51	Married	On sick leave	0	Secondary
13	Female	50	Cohabiting	Nurse	100	Higher education
14	Female	22	Couple living apart	Salesperson	100	Secondary
15	Male	24	Cohabiting	Unemployed – seeking employment	0	Secondary
16	Female	42	Married	Educator	100	Higher education
17	Male	52	Married	Technical support	100	Higher education
18	Female	58	Married	Pharmacist	88	Higher education
19	Female	52	Married	Assistant nurse	75	Secondary
20	Female	28	Cohabiting	Assistant nurse	75	Secondary
21	Female	60	Married	Office worker	100	Secondary
22	Female	61	Single	On sick leave	0	Primary
23	Male	64	Married	Administrative work	100	Primary
24	Male	60	Married	Construction worker	100	Secondary
25	Female	64	Married	Disability pension	0	Primary
26	Female	64	Married	Disability pension	0	Primary
27	Male	64	Married	Retired	0	Primary
28	Female	45	Single	On sick leave	0	Primary
29	Female	44	Married	Teacher	100	Higher education
30	Female	58	Single	Accountant	75	Primary
31	Female	59	Married	Metal worker	100	Primary
32	Male	53	Married	Carpenter	50	Primary
33	Female	63	Married	Accountant	72	Primary
34	Female	36	Single	Medical secretary	100	Higher education
35	Male	60	Single	Disability pension	0	Primary
36	Male	58	Married	Salesman	100	Secondary
37	Female	60	Married	Assistant nurse	50	Primary
38	Male	53	Married	Electrician	100	Primary
39	Male	64	Single	Administrative work	50	Secondary
40	Male	37	Married	Welder	100	Secondary
41	Male	53	Married	Manager	100	Primary
42	Male	46	Married	Private company	100	Secondary
43	Male	60	Married	Electrician	100	Primary
44	Male	57	Cohabiting	Engineer	100	Higher education
45	Male	62	Married	Engine operator	100	Primary
46	Female	59	Single	Job seeker/on sick leave	0	Primary
47	Female	55	Single	Work coach	100	Secondary
48	Female	58	Single	Educator	100	Secondary
49	Male	59	Married	Salesman	96	Primary
50	Female	56	Married	Assistant nurse	100	Secondary
51	Female	63	Married	Disability pension	0	Secondary
52	Female	39	Married	Assistant nurse	75	Secondary
53	Male	58	Cohabiting	Industrial worker	100	Secondary
54	Female	63	Married	Bank employee	90	Primary
55	Female	57	Married	Youth worker	75	Secondary
56	Female	56	Married	Union work	100	Secondary
57	Male	54	Couple living apart	Politician/farmer	100	Secondary
58	Male	26	Cohabiting	Industrial worker	100	Secondary
59	Male	43	Cohabiting	Salesman	100	Secondary

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

Meaning unit	Condensed meaning unit	Code	Sub-category	Category
When I carried [my daughter], when she was younger, I was afraid that I would drop her.	Scared to drop daughter when she was younger	Fear of dropping child	Symptoms restricting physical interactions with my significant others	Physical interactions with significant others
When I feel that I cannot manage, then the ones at home have to accept, and they do since they know how it is.	The ones at home have to accept when I cannot manage	Family has to accept	My significant others have to adapt	My early RA causes activity adaptations for us all

Table 3. Categories and sub-categories found in relation to significant others’ impact on participation in early RA.

Categories	Sub-categories
My early RA causes activity adaptations for us all	My significant others have to adapt Keeping our relationship stable
Making the significant others balance between shortfalls and participation	My significant others’ interpretation of my need for assistance My significant others can facilitate participation
Physical interactions with significant others	Symptoms restricting physical interactions with my significant others We find ways to manage body contact
Emotions in relation to activities with others	How will my significant others and I manage everyday life in the future? Being a burden to significant others Taking negative feelings out on my significant others I feel like I am failing my significant others in common activities

Results

These results describe the participants’ experiences of their significant others’ influence on participation in everyday life. Four categories and ten sub-categories were revealed (headings as detailed in Table 3) in the analysis of the interviews. Each category has been described below with the participant quotes. According to the participants, their significant others had different types of impact on participation. The participants reported their significant others to sometimes act as facilitators for participation, and sometimes as more of a barrier. The impact described by the participants concerned adaptations made in everyday life, the balance experienced by the participants between feeling involved and being in need of help, interactions with significant others including physical contact, and emotions related to activities with significant others.

My early RA causes activity adaptations for us all

The participants described that they and their significant others often had to adapt their everyday life as a consequence of early RA. The participants’ limitations were necessary to accept and adapt to for both the participants and the significant others. However, the participants also mentioned that the impact the diagnosis could have on their everyday life was manageable and no major changes in activities and relationships were needed at all.

My significant others have to adapt

According to the participants, the significant others were forced to adapt to the situation following the diagnosis. The ones they shared their household with had to take over some duties, about which the participants often could sense some resistance. The unwillingness to adapt to the new circumstances was perceived as children not fully understanding the influence of early RA on their physical condition and limitations, or family members not accepting the diagnosis or misunderstanding symptoms. “The kid likes to build tree houses [—] you cannot always do that, so you have to skip it. Then he gets cranky when you cannot build the day he wants to” (Participant no. 40) “... then you sit down, then it’s like you could fall asleep straight away. Maybe they [family] feel that I’m lazy, [—] that I’m hiding, away from chores” (Participant no. 42). The participants also described the aspect of overprotection versus demands, in their significant others’ way of adapting: “Sometimes she [wife] acted overprotective and you got the feeling that she doesn’t think that I can do anything...in other situations I couldn’t manage what she had set out for me to do” (Participant no. 4). In cases like these, the significant others were perceived as having a more negative influence on participation and acting as a type of barrier. The participants described how persons in the same household might have to give up old routines in order to facilitate participation for the person with RA,

for example not going on trips as often as before the diagnosis, as described by one man: “... they [wife and children] can’t ski that much, that’s one thing [—] it’s of big importance to me anyway, you have to adapt, eh, they have to adapt a bit to me...” (Participant no. 10). However, not all changes that had to be made were performed with a negative approach. The participants described that their significant others also could be open to adaptations and changes, for example:

...it’s not a problem, but you make the best out of it, we fix something else or we do it in a different way, so it always works out because they [wife and children] know how it is at home so it’s not a problem. (Participant no. 17)

Several participants mentioned younger children as more positive when activities had to be performed in a new way, as exemplified by one woman: “He [grandchild] likes to drive around with cars on the floor, and he wants you to crawl around and drive. But most of the time I just sit in one place, but I drive around anyway so he thinks that’s fine” (Participant no. 19).

Keeping our relationship stable

Despite the new situation and the impact that RA could have on everyday life, many of the participants stated that relationships with significant others continued as before. A stable relationship could include being able to make adaptations together, or continuing as before the diagnosis without recognisable adaptations. The participants expressed feelings such as being understood, leading to the significant others acting as facilitators for participation. For example, group activities might take a different shape in order for the persons with early RA to be able to take part:

We [group of girlfriends] can have a whole day out, walking, but I can’t do that anymore [—] sometimes we have brought our bikes instead, they are nice, my friends, so now we have taken bicycle trips instead, because that I can manage much better. (Participant no. 6)

Also, the new situation could be described by the participants as neutral for the family, once everyone was informed about the diagnosis: “It’s not a big deal for our kids, I don’t think, well, they know I take medication because I’ve got rheumatism [—] when we had explained to them what kind of disease it was, so no, it’s pretty natural.” (Participant no. 29).

Making the significant others balance between shortfalls and participation

The participants distinguished situations where they received help from significant others without requesting it, from situations where everyone was helping each other out. In some of these situations, receiving help was experienced as degrading, but sometimes it included a possibility to feel more involved. The influence on participation could, therefore, be both positive and negative.



### *My significant others' interpretation of my need for assistance*

Help or assistance from significant others could be experienced as negative by the participants. Unrequested help was sometimes described as humiliating or as being forced on the participants without their wish or permission, as exemplified by a man receiving such help from his siblings: "They [sisters] came anyway and helped me, even though I could do it myself, but they didn't trust me." (Participant no. 2). Some of the participants also described an uneasy feeling when it came to needing assistance. Coming to terms with the need for assistance was described as difficult. Particularly partners or spouses could be very keen on helping with different types of activities, such as dressing or carrying shopping bags. The participants described how they were encouraged to ask for help when needed, to which a feeling of resistance sometimes was experienced. This resistance could be related to pride or the feeling of humiliation at not being able to manage the activity on your own as before. "It felt terrible to say, [boy-friend], can you come here and put my socks on [—] it felt so demeaning, then I'd rather struggle for half an hour to get my socks on" (Participant no. 9). Examples of activities where the significant others needed to help were opening lids, house cleaning and cutting up food. The participants reported grocery shopping to be a common activity where assistance was needed, and in particular carrying shopping bags. Lifting heavy objects, such as furniture, was also usually problematic. Some participants also mentioned problems with self-care, such as personal hygiene, or dressing. "It happens that my partner has to help with clothes when that kicks in, sometimes my shoulder hurts too badly and then I can't get the jacket on, so then he needs to do it." (Participant no. 6). On the other hand, getting help could also have a positive input, as one participant mentioned: "It feels very pleasant, I must say, that they [family and grandchildren] help me ...". (Participant no. 51).

### *My significant others can facilitate participation*

Even if the participants were in need of help in different ways, they described how their significant others could approach the situation in ways that were positive and not degrading. Then the participants described a feeling of being more involved in the activity and that all members in the family, both adults and children, were helping each other out, and thereby facilitating participation in everyday life for the participant. This can be exemplified by the sharing of domestic tasks such as doing the laundry: "... then I hang the laundry and he [partner] gets to take care of the big, heavy, like linens [—] we distribute the chores since this is our world all the time, it's like a natural distribution..." (Participant no. 12). The possibility to share activities such as household work, gardening, and taking care of animals, were examples given by the participants where they expressed a feeling of belonging and making a difference. But also more social events could make the participants feel involved and that they were able to contribute, as exemplified by one man attending sports practice together with his father and friends: "I go to practice and do my thing, and when I feel that I need to slow down, I fill up the water bottles and help out" (Participant no. 15). The participants also described involvement in activities as a feeling of being needed by their significant others and being able to contribute. In these situations, the significant others could facilitate participation by the distribution of specific tasks according to the participants' abilities, and thereby making them feel involved. "Me and my sister are there sometimes to help her [mother]. My sister cleans up and I help her [mother] in the shower" (Participant no. 25).

### *Physical interactions with significant others*

According to the participants, physical contact with their significant others, such as sexual contact, or carrying and comforting children, could cause problems. However, the participants also mentioned that they had found ways to make physical contact manageable and that they could continue to interact with their grandchildren or be intimate with their partner.

### *Symptoms restricting physical interactions with my significant others*

The participants described how symptoms caused by early RA could have a negative impact on interactions with significant others in terms of physical contact. This could include being intimate with their partner, lifting, or holding their children or grandchildren, or receiving hugs of an unwanted and tough nature from their significant others. The fact that the participants could not perform activities together with their significant others in a desired way, could lead to frustration, as well as sadness and disappointment. "The youngest grandchild, she's four now, that I couldn't lift her up, as much as I wanted to. That was the toughest part" (Participant no. 46). In addition, the aspect of their significant others misunderstanding symptoms, and therefore, acting as a barrier for participation, added to the negative feelings that could follow the limitations in physical interactions with their significant others.

...towards my wife, it's not always you're able to meet her, both sexually and everything, it's really ... it's limited sometimes [—] when I'm in pain it doesn't work and then, that's the hard part, she [wife] thinks. That's why I think she doesn't accept the disease (Participant no. 32).

On the other hand, even though the participants expressed difficulties with physical interactions, they could still experience their significant others as facilitators for participation when they were met with a more understanding attitude.

... you kiss and you hug but it can stop there, you don't have to take it any further [—] most times I have it my way, he [husband] is very understanding, I have to say, it's not that easy to understand [—] I feel that I dare to tell him [husband] that no, tonight I'm in too much pain so don't even think about ... but you can hold me, and I mean just lay down and hold each other and maybe kiss and hug, that's enough. (Participant no. 20)

### *We find ways to manage body contact*

Not all participants experienced problems when it came to physical contact, or they had discovered means to handle the activities in a way that was still satisfactory to them. Participants reported that their significant others had started to think twice before grabbing their hand, and they had found solutions to solve potential issues concerning intimate life, thereby facilitating participation in activities. One participant described:

... it happens, I have to think about that today I'm in pain, sure [—] I can't say that I have to say 'stop' or 'no' or something for the intimate part [with partner], it's just that you have to find other solutions ... (Participant no. 15)

Many of the participants described a process where activities involving physical contact had been difficult in the very early stages of RA when they had just received their diagnosis, but the activities had become easier to perform later on. "I don't think it's ... it's absolutely nothing I worry about nowadays ... hugging [husband] could hurt before, and that was not nice. But otherwise I don't feel that it's anything." (Participant no. 16). At the same time, the participants described that interacting with children or

grandchildren could become easier as the children grew older, and could walk by themselves and got a better understanding of the situation. "Now it's fine, now she [grandchild]... when she was a baby, it was a bit hindering, to carry her when she was little, but now, she's two and a half so..." (Participant no. 33).

### *Emotions in relation to activities with significant others*

The participants described different types of feelings in relation to interaction and activities with their significant others. They described how negative feelings were taken out on others, as well as the feeling of being a burden or failing others. The participants also revealed worries about their possibility to participate in common activities, and how it might affect everyday life and their relationships with others.

### *How will my significant others and I manage everyday life in the future?*

The participants expressed worry about the future and how the diagnosis of RA might affect the relationships with their significant others. These worries could include a fear that a partner might leave if the body changed or if one's appearance worsened, or uncertainty regarding one's ability to work, but also anxiety about how to be able to interact with children in everyday life.

I'm scared that it might be that bad that I have to be in a wheelchair and that I can't handle working life, and handle the children, I want to function for their sake, I want to see them grow up... (Participant no. 20)

One major aspect of worrying that the participants mentioned, was the thought of not knowing if or when the diagnosis could get worse, and how that might affect the family and everyday life.

...if it's going to get worse, that's the situation you have to face [—] I might have to stop working, you don't know, those are the thoughts we discuss maybe most about my disease, she [wife] notices too that I'm feeling very good, but for how long, that you don't know... (Participant no. 36)

### *Being a burden to significant others*

The feeling of making life difficult for others and the frustration that came with it, was expressed by the participants. This feeling appeared through situations when significant others were sad on their behalf, or did not want to be of assistance any longer, or when the participants tried to hide the pain in order not to be a concern for their significant others. "... only if they [children] see that it's swollen or something [—] if they don't see I don't say anything, I don't want that, they have their own concerns" (Participant no. 31). In addition, a sad feeling of not being able to take care of oneself and an extra load being put on significant others, was described by one woman in situations when she needed assistance from her daughter-in-law: "It's hard, that I can't even brush my teeth always, for example, it's really hard, you're like a little child." (Participant no. 28). Participants also described a disappointment when a partner had to do more housework because the participant had to rest or sleep. For example, "When I'm home [from work] she [partner] feels that we should share house chores but then I've been sleeping a lot" (Participant no. 58).

### *Taking negative feelings out on my significant others*

The participants described how situations sometimes occurred when frustration and aggression were aimed at their significant others, and that a sense of sadness and shame appeared afterwards.

This aggression usually came from being in pain and the frustration over not being able to manage daily tasks the desired way. "You don't know where it [the frustration] goes sometimes, of course you can get pissed off, then it's like that, the family [wife and children] has to take it, sadly" (Participant no. 10). Also, in a situation when pain and frustration are involved, it could be easy to scream at young children, as exemplified by one woman:

... maybe I'm not angry at the children but I might scream at him [son] instead because I'm angry at the situation, because of something he's just asking and it's all because I am, or have been in, a heck of a lot of pain. (Participant no. 20)

However, significant others could also respond to these situations with support and encouragement, and help the person find a way to get past the negative feelings, acting as facilitators for participation. "Mum and dad had to hear a lot of rubbish, I was pretty low [—] family and friends kind of pushed me to come back" (Participant no. 15).

### *I feel like I am failing my significant others in common activities*

The feeling of not being able to help with tasks, or not being there for a significant other, was expressed among the participants. Due to stiffness, pain, fatigue, or difficulties with fine motor skills, problems appeared in interactions with children and grandchildren. A sense of failing others occurred both when it came to showing support and during activities involving sports or play, causing feelings of sadness and disappointment.

Then we sit on the floor, building and stuff [—] then all of a sudden he [grandchild] runs off and I can't get up, I've been sitting on the floor for too long [—] and he shouts 'come on grandma, come on grandma', but I can't. (Participant no. 13)

The participants described that the experience of failing significant others also could involve not being able to participate in household work and therefore, feeling that one did not give enough support. This could be particularly noticeable if a couple was used to doing certain activities together, and now the person with RA could no longer help with that part of their common daily life. "He [partner] always had to go shopping, he had to do everything that needed to be done, which felt terrible since you're used to doing that together" (Participant no. 9). Participants also described how they could feel inadequate in leisure activities and heavier tasks like different types of renovations.

He [partner] gets to do a lot and I can't do what I have been able to before [—] before we met I have renovated houses by myself [—] it's a bit sad, we have discussed, it's a bit tough that you're not enough, for things you were able to do before. (Participant no. 13)

## **Discussion**

The participants in this study described how their significant others had to adapt to the consequences during the first three years after diagnosis of RA, and how the significant others could facilitate or hinder participation in everyday life through their attitudes and actions. The participants gave examples of situations when significant others acted in a facilitating way, such as distributing chores or adapting activities to meet the participants' abilities, as well as reacting to the participant's negative feelings in a supportive manner. On the other hand, the participants also gave examples of how the significant others could hinder participation, by helping without asking or taking the symptom of fatigue for laziness. The social environment being perceived as both facilitating and hindering for participation have previously been reported

mainly in established RA [2,3,23]. This study highlights the matter of significant others being experienced by persons with RA both as supportive and as a potential barrier even during the earlier stages after diagnosis.

The results showed that the participants often described their significant others as having difficulties with finding a balance between acting in overprotective or demanding ways. "Encouraging to ask for help when needed", indicates that the intention is to be kind and assist in a positive way. However, by pointing out that the person is in need of help, the significant other might unintentionally have a negative influence and hinder participation. This negative effect can be assumed to depend on lack of information, which is a previously reported problem [14,23]. The results of Kristiansen et al. [14] indicate that adjustments are necessary for both the person with RA and a partner, and when the partner does not understand or accept relationships might break down. Similar experiences of troublesome relationships were referred to in this study. However, positive effects of adjusting to the new situation have been reported by Fallatah and Edge [24], where significant others adjusting to the diagnosis of RA had a positive effect on the relationship. This can also be seen in this study when adaptations were experienced as good for the relationships between the participants and their significant others.

When it comes to physical contact and intimate life, the participants experienced some difficulties, both physically and emotionally. Sexual health is reported to be an important part of a person's quality of life and previous research shows that persons with a rheumatic disease perceive their health status to impact their sexual activity. In some cases, even to the point where sexual activity cannot be performed [25]. The participants of this study, however, also described how they had found solutions to still being able to perform these types of activities, despite possible limitations. Although, from a clinical perspective, it is also important to give the patient the opportunity to discuss potential sexual issues. Health care professionals have previously been reported to partly fail in their communication about sexuality, and it is of importance that the person experiencing disabilities is given a holistic treatment [26].

The participants described negative emotions perceived by both themselves and their significant others in relation to participation restrictions, for example, the disappointment shown when some activities need to be terminated or performed less frequently. This is in accord with previous studies about living close to a person with established RA [27], where significant others reported how they became emotionally affected when social activities had to be avoided. From the significant others' point of view, there is an initial distress at seeing the person with early RA in pain, as well as a need to give practical support [7]. This is in line with the perceptions of the participants in this study. However, they also stated that negative feelings might be turned upside down if significant others met these feelings in a positive and supportive way.

Previous research on both early [15] and established [14] RA shows that being in need of assistance can lead to mixed emotions as the person is grateful for the help but at the same time feels guilty for needing it [14], and thereby can feel like being a burden to others [15]. This is referred to in this study, although, the participants also described situations when they instead felt supported by their significant others, for example, because they facilitated participation in household work. Making the participants feel useful was an important way in which significant others could act as facilitators for participation, making the person feel

involved in the activity. Similar feelings have previously been expressed by persons with established RA, who report a need to be able to do things for others in order to feel useful [28], and a wish to be able to contribute despite the diagnosis [13]. In addition, the feeling of contribution has previously been closely connected to the essence of participation by persons with different types of disabilities [29].

In this study, the participants described how they perceived that their significant others misunderstood the situation and symptoms, such as mistaking fatigue for laziness. According to several studies where significant others were interviewed, lack of knowledge and information about the symptoms of RA is reported to cause an initial negative reaction to the diagnosis [7,24]. In addition, quantitative research shows that it is not uncommon for significant others to over- or under-estimate fatigue, pain, and physical limitations [30]. Consequently, a need to reach persons in the social environment in order to give qualified information about the diagnosis has previously been pointed out [7]. Considering previous studies, identifying the lack of information on the significant others' behalf [27], as well as the results of the present one, this highlights the importance of involving significant others in the rehabilitation process of persons with RA.

Today there is an increased demand for the healthcare system to involve the patient in the planning and coordination of the treatment, where the patient takes on a professional role [31]. However, the involvement of significant others is also needed, and regulations such as the Swedish Patient Act clearly states that the significant other has as much right to information as the patient, as long as it does not interfere with professional confidentiality [32]. In addition, clinicians report that if the patient and carer or significant other are given more information and education, they can take a bigger part in the healthcare and rehabilitation process [31]. Even though the involvement of significant others in the rehabilitation process was not specifically explored in this study, a lack of information and understanding was revealed. Furthermore, the value of significant others in the process and the importance of healthcare professionals informing and supporting them, has recently been highlighted when it comes to other diagnoses [33]. Therefore, ensuring a collaboration involving the person with early RA, significant other and healthcare professionals, should become part of clinical practice. This in order for significant others to be able to further facilitate participation.

### **Methodological considerations**

One of this study's strengths is the large body of material from which information was gathered. Fifty-nine participants sharing their stories gives a broad basis for knowledge about persons with early RA and their everyday life, including their interactions with significant others. This sample size of persons in their first years of living with the diagnosis offers a great opportunity when it comes to gaining insight into their experiences during the first sensitive years. The TIRA project has followed the participants since diagnosis, giving the researchers the possibility to focus on early RA. The definition of early RA is an ongoing discussion, but in this study, questions about the early years after diagnosis have been asked, and a rich material with experiences has been gathered. Although, the international standard of  $\leq 12$  months disease duration as early RA has been used, since the participants were included in the TIRA cohort during their first year since diagnosis. Thereby, the TIRA project is viewed as an early RA cohort. The classification criteria are originally developed for scientific purpose



in order to support communication. These criteria are from the beginning not aimed to be used in clinical practice. However, the ACR criteria are nowadays sometimes used in clinical setting for diagnose. In the TIRA project, the choice has been made to do small exceptions from the ACR criteria.

Three authors performing the interviews might potentially imply inconsistency in the material, and can be considered a limitation. However, the interview questions have been developed by a large part of the research group together and practically it would have been a demanding job for one person to perform all the 59 interviews. One strength is also the five pilot-tests made prior to the interviews, which helped to develop the interview questions further. The three authors who performed the interviews (AS, EV, and GÖ) have all been involved in the process of preparing this manuscript; however, the first author (MBe) who performed a large part of the analysis was not involved in the interviews. This can be argued to increase the confidentiality for the participants since the first author did not meet or see the interviewees. Also, this means that body language or tone of voice were not taken into account when performing the analysis, keeping the results closer to what was said, rather than what body language might imply. In order to ensure credibility [22], the sub-categories and categories formulated by the first author (MBe) were checked and re-formulated in discussions with the coauthors in several rounds. Authentic quotes were used to increase trustworthiness [34]. This was done in order to show the reader from what category the data were formulated, but at the same time, quotes were chosen that would not identify the participants. Special attention was given to formulating the results and discussion to clearly show that they are based on the participants' views and thoughts about their significant others.

The participants of this study do not represent the gender distribution of RA, since the diagnosis more often affects women [35]. In this study, the intention was not to represent the gender distribution of the general population. Instead, a more even distribution was aimed at, in order to get a rich material with a broader set of experiences. With another gender distribution, the results might have looked different. Some issues or situations could have been more pronounced, but some might also have been missed if the distribution had been another.

Since qualitative research on the first years after diagnosis of RA and participation is limited, especially in relation to significant others, this study provides an understanding of how participation can be facilitated and what impact the significant others have on participation in everyday life. However, only persons with early RA participated in this study, and only their feelings and opinions were researched. Since the results show that the communication with significant others is an important point for persons with early RA, it is suggested that also the feelings and opinions of the significant others should be investigated. Therefore, further studies that focus on the experiences of significant others should be performed. Qualitative studies can provide a deeper understanding of their viewpoint, while quantitative methods can present clear comparisons of different aspect of the subject, such as support and participation.

## Conclusions

Significant others can facilitate as well as hinder participation in everyday life for persons already during the first years after diagnosis of RA, through their attitudes and actions. Adapting activities with a positive attitude can be a way to facilitate participation, whereas misunderstanding symptoms or pointing

out a need for help can hinder participation. In order to enhance participation in everyday life for persons with early RA, the understanding and support of significant others are important. Therefore, there is a need to identify when and how the significant others can be involved in the rehabilitation process, and to ensure that they have access to correct information about the diagnosis. This would give them the best opportunity to act as facilitators of participation early in the disease process.

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