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**Emotions related to participation restrictions as experienced by patients with early rheumatoid arthritis: A qualitative interview study (The Swedish TIRA study)**

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## **Abstract**

*Background:* Psychological distress is a well-known complication in rheumatoid arthritis (RA), but knowledge regarding emotions, and their relationship to participation restrictions, is scarce.

*Objectives:* The aim was to explore emotions related to participation restrictions in individuals with RA.

*Method:* In this study, 48 patients with early RA, aged 20-63 years, were interviewed about participation restrictions using Critical Incident Technique. Information from transcribed interviews was converted into dilemmas and linked to ICF participation codes. The emotions described were condensed and categorized.

*Results:* Feelings of grief, fear, aggressiveness, and shame were expressed in relation to RA-related participation restrictions. Hopelessness and sadness were described when trying to perform daily activities such as getting up in the mornings, getting dressed, or not being able to perform duties at work. Sadness was also experienced in relation to not being able to continue leisure activities or care for children. Examples of fear descriptions were found in relation to deteriorating health and fumble fear, which made the individual withdraw from activities as a result of mistrusting the body. Anger and irritation were described in relation to domestic and employed work, but also in social relations where the individual felt unable to continue valued activities. Shame or embarrassment was described when participation restrictions became visible in public.

*Conclusions:* Feelings of grief, aggressiveness, fear and shame are emotions closely related to participation restrictions of RA in everyday life. Addressing emotions in research and in corresponding multi-professional interventions are necessary in order to further develop the patient's perspective of RA.

*Keywords:* critical incidents, lived experiences, feelings, participation, patients' perspectives

## **Introduction**

Rheumatoid arthritis (RA) is a chronic disease where limitations and restrictions in everyday life are commonly experienced [1-6]. Medications for RA have developed greatly during the past century [7], and new biological agents have extensively reduced disability due to RA [8]. In spite of significant advances in drug therapy, RA patients still report pain [9], and at least half of all RA patients experience psychological distress such as anxiety and depression [10-12]. Studies have shown that psychological distress is a recurrent problem for RA patients and that, unlike disease activity, symptoms of pain, stiffness and functional impairment are significantly associated with levels of psychological distress [12]. The findings from different studies are, however, contradictory. Overman et al. [13] found that psychological distress and disease activity were positively associated. Research has also shown that patients' emotions and support from family and friends play a crucial role in the course of RA [14, 15], and that negative emotions appear to be recurrent experiences in relation to RA [16]. The way psychological variables influence health is hard to measure and research methods need to be developed further before this relationship can be understood [17]. Recording and understanding patients' emotional experiences of RA in everyday life is a field now beginning to be researched. A recent and important initial study has been performed by the National Rheumatoid Arthritis Society (NRAS) who focused on emotions, relationships and sexuality [18].

The knowledge that patients' experiences enrich both research and clinical practice is not new [19]. However, a current challenge in RA research is to find methods of collecting and making use of the information contained in patients' expressed emotional experiences. OMERACT 9 concluded that life impact measures (LIM) need to be developed in order to strengthen patients' perspectives in rheumatology [20]. Collecting information on individuals' experiences in specific situations, termed critical incidents, has been continued since the 1950s [21]. In critical incident studies, information on dilemmas, consequences, and strategies for handling situations are usually collected. RA patient-experienced dilemmas have previously been described in relation to work [22]. However, emotions corresponding to RA-related participation restrictions have not yet been described. In this article we aim to describe RA patients' emotions related to RA and everyday-life dilemmas, including employed work.

## **Aim**

The aim was to explore emotions related to participation restrictions in individuals with RA.

## **Materials and Method**

### *Design*

In this study Critical Incident Technique (CIT) was used, which is a qualitative research method that collects data on life experiences in defined situations [23]. CIT has been applied in research on patients with different medical conditions [22-24], and in research on emotional experiences [25] and emotional work [26] in patients and professionals. Data were

collected through semi-structured individual face-to-face interviews. International Classification of Functioning, Disability and Health (ICF) has been used as an analytical tool for coding patient-described participation restrictions. According to ICF definition, participation is involvement in a life situation, and participation restrictions are problems an individual may experience in these situations [27].

Participants for this study were recruited from the 522 patients that were included in the second cohort (TIRA-2) of the prospective multi-centre early arthritis project with the Swedish acronym TIRA [5, 22] during 2006-2009. At inclusion, at 3, 6 and 12 months after inclusion in the TIRA study, and thereafter yearly, information concerning disease activity, disability, genetics, and on going disease modifying anti-rheumatic drugs were recorded. During the study period, patients were offered treatment including pharmacological intervention, physiotherapy, occupational therapy, and social counselling depending on individual needs.

Specific inclusion criteria for this study were individuals between the ages of 20-63 years who had recently reached three years post RA diagnosis. Patient recruitment started in 2009 and initially included the 128 patients who participated in TIRA-2 during 2006. Of these, 53 patients fulfilled the inclusion criteria and were asked to volunteer for the study. Eleven patients, eight women and three men, declined to participate due to either lack of time, not experiencing RA-related dilemmas in their daily life, or lack of interest. In addition, the first six patients from the centre who reached their 3-year follow-up during 2010 were also asked to volunteer. None declined resulting in a total of 48 patients. Socio-demographic characteristics at the time of diagnosis are shown in Table 1.

#### *Data collection*

After pilot testing the interview questions on five RA patients minor changes were made. Interview location was chosen by the informant. The following central questions were used: can you describe how your everyday life works? Can you describe an occasion in your everyday life, preferably during the last week, when you were hindered by or reminded of your RA? Follow-up questions allowed the patients to describe their situation and dilemma consequences in more detail, such as what happened and what thoughts and feelings were experienced (the interview guide is available upon request). Interviews lasted between 45 and 90 min, were digitally recorded and transcribed verbatim. The interviewers (EV, AS, GÖ,) were not involved in the clinical treatment of the patients.

#### *Data analysis*

The transcribed interviews were read and the description of dilemmas were abstracted from the text and placed in tabular form by the three interviewers (AS, EV and GÖ). Then, these dilemmas were coded by two of the researchers (MT and EV) according to the updated ICF linking rules [28]. The term participation is used to denote the performance of activities within context, from simple actions such as lifting an object to complex actions such as work and family relations, according to option 4 of annexe 3 of the ICF. The prefix 'p' is added to the numerical codes in the results section to denote a participation aspect [28].

In the next step of the analysis, the interviews were analysed using qualitative conventional content analysis [29], where the interviews were read word-by-word and then coded by two authors (GÖ and AS). Next, the interviews were re-read with focus on the patients' described emotions in relation to the dilemmas described. Emotional descriptions were found in 40 of the 48 interviews. Of the eight RA patients not using emotional expressions, five were women and three were men. The condensed data were grouped into four categories of emotions based on nine subcategories (Table 2). In the results section, the ICF participation codes relating to the emotions described are included in the text.

### *Ethical considerations*

The study was approved by the Research Ethics Committee of the Faculty of Health Sciences, Linköping University, no. M168-05 T84-09, Sweden.

## **Results**

Four different types of emotions were found in the RA patients' descriptions of participation restrictions: feelings of grief (Table 3), feelings of fear (Table 4), feelings of aggressiveness (Table 5), and feelings of shame (Table 6). These emotions were described in relation to everyday tasks and experiences, which meant that some participation restrictions were repeated when patients had mixed feelings or when some were sad and others were angry in similar situations. Feelings of grief and feelings of fear were most commonly described in relation to participation restrictions, and feelings of shame were less commonly described.

### *Feelings of grief*

#### Hopelessness

Patients described hopelessness when they could no longer perform functions they had relied on previously, such as when getting out of bed in the morning, going to the toilet and getting dressed. Hopelessness was experienced when facing problems with carrying, cuddling, playing, and spending time with grandchildren. In relation to employed work, hopelessness was described when having problems performing work tasks, ordering sawn goods, walking quickly, or when needing to rest during the day. During leisure time, hopelessness was described when experiencing difficulty jogging, walking the dog, and watching showjumping. Hopelessness was also experienced in relation to problems with sex and intimacy.

I. "My sex life is limited, does not work at all, sometimes because of pain and fatigue. I try to withdraw, reject her. I am a failure" (EV21M)

#### Sadness

Sadness was experienced in relation to having difficulties kneeling, walking barefoot, descending/ascending stairs, and driving the car to visit friends. Sadness was also described when experiencing difficulties taking a long walk, shopping for food, and when having to use slippers instead of shoes. Having difficulty chopping firewood, hoovering, or taking care of horses was also related to sadness. In relation to employed work, sadness was described when

losing work due to lack of adjustments, experiencing difficulties with carrying and gripping tools, or difficulty continuing work. Sadness was experienced when having to stop playing golf, visit a late cinema show, ride, do physical exercise, go dancing or fishing. Sadness was also described when having to refrain from playing soccer with grandchildren, carrying, driving grandchildren, or assisting children and relatives.

II. "I don't have the energy to be with my grandchildren, I don't have the energy to answer questions, the children become sad, I become sad, why did I say that to them." (EV17W)

### Insufficiency

Insufficiency was described in situations that included experiencing difficulties with shopping and carrying grocery bags, or cooking meals. Insufficiency was also related to difficulty remaining in a sitting position, or when not enjoying cuddling loved ones. Insufficiency was also expressed in relation to work when experiencing difficulties with handling screws and tools, or when having to refrain from walking home from work and losing contact with colleagues when on sick-leave.

III. "Tougher to walk home from work, I would like to go out walking and feel no pain." (EV22W)

### *Feelings of fear*

#### Illness fear

Illness fear was expressed in relation to not being able to take care of one's health, in becoming worse, and being unable to take care of others. Illness fear was related to thinking about potential increasing sleeping problems, having to reveal RA at work if work capacity diminishes, or being unable to continue voluntary work. Illness fear was also experienced in relation to not being able to shake hands or walk the dog. Illness fear was described in relation to losing companionship if no longer able to experience leisure time with friends, or being unable to have sex or intimacy. Illness fear was also described in relation to catching colds.

IV. "Something that stops me is seeing my grandchildren when they have a cold, because for a while I just soaked up bacteria, that is, I am afraid of getting sick, there I have, there I am extremely careful, for a while I was very susceptible as soon as someone had a cold." (GÖ2W)

#### Fumble fear

Fumble fear was a recurrent emotion described in relation to situations where the patients were afraid of fumbling, falling or letting go of something or someone, such as fumbling when walking, while shopping or with friends. Fumble fear was also present when caring for horses - letting them in or out - and when shoveling dirt or going to the gym or adventure pool. Fumble fear made it less possible to participate in those activities the individual used to enjoy. Fumble fear was also related to choosing to refrain from carrying things or children or grandchildren.

V. "It bothers me that I have difficulty putting my grandchild on the bike, it's the feeling of being unable to do it which is hard." (AS1W)

### *Feelings of aggressiveness*

#### Anger

Anger was expressed when having difficulty opening plastic bottles, peeling potatoes, gardening, or threading a needle. Anger was also expressed in relation to employment - experiencing difficulties in continuing to work, and in specific work tasks such as walking with social service clients. Patients also described how anger resulted from being refused money at the bank when they were unable to sign the cash withdrawal form, or when receiving contradictory information from professionals. Not being able to enjoy sex and intimacy anymore also made some patients angry. Anger was also expressed in relation to not being able to continue to play musical instruments, or when failing in taking care of oneself and relatives, specifically with Christmas preparations and other home duties.

VI. "I was going to make a 'Jansson's Temptation' [a typical Swedish Christmas dish] for Christmas. I was going to peel a kilo of potatoes, but my fingers get stuck and I get cramps, and my fingers lock. I get irritated and angry, I want to finish and not spend the whole day making one 'Jansson's Temptation'." (AS8W)

#### Irritation

Irritation and frustration were described in relation to sleeping problems or when experiencing difficulty opening doors or gripping tools. The patients described being irritated by restrictions when using stairs, or having problems using public transport, carrying goods or shopping. Restrictions and limitations in taking care of the house and pets were other situations in which irritation was described. The patients also described irritation when not being able to socialize as much as they wanted to with family and with friends.

VII. "When I am invited out in the evening and there is nothing special happening, then I can become very tired, it's something I do not really recognize about myself and that makes me irritated." (AS5W)

### *Feelings of shame*

#### Embarrassment

Feelings of shame such as embarrassment, and feelings of exclusion were described in relation to public appearance. Embarrassment was expressed in relation to no longer being able to restore and repair the house or having difficulty standing up from a sitting position at parties or meetings. Embarrassment was described in relation to being unable to go jogging with friends or when visiting public WCs. It was shameful not being able to help out at family reunions, let others see them limping, or show that working on the sales counter had become impossible. Embarrassment was described when not being able to conduct general tasks in



organized meetings, having to do physical exercise in public, and being unable to care for one's children.

VIII. "I could not have both kids at home when I felt bad due to my RA. I was at home with my daughter and left my son at kindergarten. He did not like it there at all and I felt really guilty about leaving him there." (EV9W)

### Feelings of exclusion

Feelings of exclusion were described when not being able to act like everyone else, for instance, when not being able to take long walks with the dog and the stroller. At work, exclusion was experienced when not being able to increase work pace, or when not being able to carry and use the stairs. The patients described feeling different and excluded when not being able to wear the right type of shoes, when having problems visiting arenas and cinemas, or when not being able to dance and party as before. One patient described feeling like a second-class citizen due to not being economically self-sufficient. In the quote below, worries for the future [illness fear] is also a recorded emotion.

IX. "Thinking about the future ... I'm worried about the Social Insurance rules. That I would not be able to go on sick leave [receive economic benefits]. To be treated as a second-class citizen." (AS6W)

## Discussion

The present study has shown that certain emotions are commonly experienced as a result of RA-related participation restrictions. The different emotions: feelings of grief, feelings of aggressiveness, feelings of fear and feelings of shame, were often experienced during social interactions with relatives, friends, workmates, animals, or the public. The described feelings could be interpreted as ordinary reactions to the daily experiences of living with a chronic illness rather than psychological impairments. Most emotions were related to interaction and how the individual interpreted the situation and context [30]. However, some of the feelings experienced, such as illness fear, were described as individual experiences related to worries for the future and possible increased disability.

Most of the patients in the present study were working and taking established medication, but still described sadness, anger, fear and shame. Feelings of anger and sadness pertaining to lack of function, and feelings of exclusion and embarrassment in public situations might just be normal reactions, and expressing these negative emotions might be a way of ensuring one's psychological well-being [31]. Unfortunately, RA patients with a high level of anxiety, often in combination with depression, have seldom received sufficient health care support or treatment [10]. A nursing clinic, specialized in newly diagnosed RA patients, underlined the importance of patients receiving support for their feelings, such as frustration and fear of the future [32]. Investigating psychological well-being [10-11] and emotions [33] in relation to RA is necessary to begin to understand what type of interventions patients can benefit from, and to develop interventions based on patients' experiences of everyday life situations.

Patients' emotions in relation to participation restrictions can give professionals a sense of what's important in life for specific individuals. Focusing on the context combined with verbal expression of emotions can help discover vulnerable patients. Edwards et al. [34] have shown that cognitive and emotional processes are crucial contributors to the inter-individual differences found in perception and impact of pain, and argue that depression and fear (catastrophizing) should be the target points in multimodal management and treatment of RA. Some of the patients in the present study expressed illness fear in relation to sleep disturbances. They already experienced sleeping problems and were afraid of this increasing. RA research has shown that pain and depression play a significant role in sleep disturbance [35]. However, sleeping problems might also be related to the current social situation and worries about work capacity and economic situation. Receiving help with one's financial situation and worries are of course necessary for some patients, however, some may feel this is too shameful a topic to bring up in counseling as it can lead to feelings of loss of personal power and control, not at least among men [36].

In the present study, patients' emotions often were related to situations in which others were involved, and these situations included, for instance, having to refrain from closeness and playful situations with children and loved ones. For some patients, RA also negatively influenced partnerships in no longer being able to enjoy cuddling and sex, or in losing a companionship that was previously based on conducting recreational activities together. Negative emotions in relation to RA have been previously described [16, 17, 30, 31, 37]. Hill et al. [31] found that one-third of RA patients experienced adversely affected relationships. In a recent focus group study on fatigue in RA patients, participants expressed that they had become hard live with due to their experienced negative emotions: sense of hopelessness, shame, anger and irritability, and fear [16]. Similar feelings were also found in the present study: sadness, anger, feelings of fear, and shame. This highlights that although family life of patients with RA is affected by negative feelings, research has shown that patients do not discuss family life or intimate relationships with healthcare professionals [18]. In a South African study of persons living with RA, patients' experiences were comparable to a Swedish context in describing negative feelings in everyday life; some patients expressed difficulties in intimate relationships such as discomfort in having another body in the bed [37]. In the present study, patients described having negative feelings due to RA in relation to sex and cuddling, and in relation to domestic work, family duties and caring.

Emotions are, according to ICF, defined as physiological functions of the body systems. However, an individual's strategies of handling psychosocial factors, such as coping or learned helplessness, are considered personal factors [10]. Thus emotions as body functions are found on an intra-psychological level, e.g. within the individual, and health-related behaviours are found on an inter-psychological level understood as personal factors, though not listed in ICF. In the comprehensive Core Sets of RA, emotions are present as body functions, but in the text it is said that the disease processes are related to environmental and personal factors [10, 38, 39]. ICF is neutral in relation to gender. In the present study, men talked about emotions as much as women did. Previous research has found that men use illness experiences as a way of verbally expressing emotions, unlike women [40]. These

gender differences are experienced in different ways. Men with RA experience more pressure in not being able to be the breadwinner [40]. Emotions as personal factors are not classified in ICF, nor are they listed as environmental social factors [27], but in times of increasing psychological distress we argue that ICF needs to develop the area of personal factors and include recurrent emotions that interfere with well-being. Instruments that measure negative emotions could be part of LIM, e.g. life impact measures as part of a patient's core sets [20].

### *Methodological considerations*

The patients were recruited from the specialist clinics included in the TIRA-2 cohort [5] and, based on individual needs, prescribed DMARDs. The CIT is a semi-qualitative method of collecting data that has been used in several studies [22-26], as is content analysis [29]. Moreover, the analysis was made in cooperation with several researchers in identifying emotions and dilemmas, and classifying the dilemmas with respect to ICF codes. We believe that procedure has made the results valid.

### *In conclusion*

Our results have highlighted RA patients' perspectives on their emotions, experiences and what they consider to be important obstacles in everyday life. This subject sample included a group of well-functioning RA patients, yet who still experienced limitations and restrictions in everyday life, not least emotionally. This indicates that the emotions found in the present study are not likely to be overestimated. We argue that addressing emotions in research and in corresponding multi-professional interventions and care are needed to further develop the patient perspective of RA.

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Table 1 - Socio-demographic characteristics of the 48 patients included in the study

Characteristics of the	Women	Men
Study population	34 (71%)	14 (29%)
<b>Age (years)</b>		
20-45	8	1
46-55	8	3
56-60	11	7
61-63	7	3
<b>Education</b>		
Elementary and occupational school	10	7
Upper secondary 2-years	5	4
Upper secondary 3-years	7	2
University	12	1
<b>Employment status</b>		
Full-time work	14	9
Part-time work	12	2
Unemployed or on sick leave	2	1
Temporary disability pension		
Early retirement benefit	6	1
Retired and receiving pension		1

Table 2 - Examples of coding procedures. Quotes with emotional consequences from

interviews with RA patients in Sweden 2009-2010.

Emotional Consequences	ICF* area	Subcategory	Category
The <b>emotional utterances</b> are in bold text.			
"Could not clean at home. I felt really <b>deflated</b> and <b>hopeless</b> . Felt <b>left out</b> . Very much in someone else's hands. Complete <b>powerlessness</b> "	Doing housework	Hopelessness	Feelings of grief
"Do not have the strength to be with the grandchildren, do not have the strength to answer questions, the children get upset, <b>I get upset</b> , why did I say those things to them?"	Family relationships	Sadness	Feelings of grief
"Cannot cook or vacuum. It is <b>tough</b> that one cannot carry out one's daily chores"	Preparing meals	Insufficiency	Feelings of grief
"No, not now, that is also, that's when I had, I was almost at the bottom when I got, eh, my immune system was really bad when I got in here and, asked to test for, eh, and then, was, I had three of these bad colds in a row, and that's' when I realised there was something wrong, something is messed up. Eh, and then after that I was very receptive, so I got <b>really scared</b> and like last year I got a really bad cold, so, and I am, never usually get as ill as I was then. Eh, so it's a bit like this that you have to think a bit before you visit people who are ill."	Family relationships	Illness fear	Feelings of fear
"I was going to shovel snow ... last Friday and then I got a pain in my groin and, you know, tendons and like this in the legs ... I am afraid, <b>afraid to using the same force as before</b> you know ... I want to, am afraid to use force now ... No I, crap, it's something else again you know, it's strange to lift, it is the legs and everything you know and..."	Caring for household objects	Fumble fear	Feelings of fear

"I feel very unsexy when I can hardly walk on my own and my hands are not as beautiful. I am afraid that he will leave me, I am so young and it can get this bad. I <b>get so angry</b> and think why?"	Intimate relationships	Anger	Feelings of aggressiveness
"To get down stairs is a <b>bloody mess</b> ".	Mowing around	Irritability	Feelings of aggressiveness
"Try to pretend that I have papers to sort out and then I am standing and stamp my feet to get started or I start to walk really slowly, so it can be <b>a bit embarrassing</b> sometimes.	Complex interpersonal interactions	Embarrassment	Feelings of shame
"Have had huge problems with my feet so I have not been able to ski or snowboard, so I have been at home when everyone else has been out, so I <b>feel left out</b> "	Recreation and leisure	Feelings of exclusion	Feelings of shame

\*International classification of Functioning, Disability and Health (WHO 2001).

Table 3 - Feelings of grief described in relation to participation restrictions of RA from interviews, Sweden 2009-2010.

Feelings of grief	Experienced RA dilemma	ICF description	ICF code	Number of dilemmas
<b>Hopelessness</b>	Getting up in the morning	Changing basic body position	p410	1
	Getting out of bed	Toileting	p530	1
	Getting dressed in the morning	Dressing	p540	1
	Cleaning the house	Doing housework	p640	1
	Taking care of others	Assisting others	p660	1
	Carrying, cuddling, playing, spending time with grandchildren, shopping with the family	Family relationships	p760	4
	My wife doesn't accept my illness	Intimate relationships	p770	1
	Always tired need to rest during day time, performing work, ordering sawn goods, walking with speed, carrying	Remunerative employment	p850	4
	Continuing voluntary work	Community life	p910	1



	Jogging, walking the dog, attending showjumping	Recreation and leisure	p920	3
<i>Sadness</i>	Receiving contradictory information from professionals	Handling stress and other psychological demands	p240	1
	Kneeling	Changing basic body position	p410	1
	Walking barefoot	Walking	p450	1
	Walking the stairways	Moving around	p455	1
	Driving the car to visit friends	Driving	p475	1
	Taking care of my nails	Caring for body parts	p520	1
	Getting dressed, wearing high-heels, using slippers instead of shoes	Dressing	p540	3
	Going for a long walk	Looking after one's health	p570	1
	Shopping for food, chopping firewood	Preparing meals	p620	2
	Hoovering	Doing housework	p640	1
	Taking care of my horses	Caring for household objects	p650	1
	Getting up from a sitting position	Complex interpersonal interactions	p720	1
	Too tired socialize, jogging together with friends	Informal social relationships	p750	4
	Getting up to a standing position after playing with children, playing soccer with grandchildren, carrying, driving grandchildren, carrying and comforting my daughter, assisting children and relatives	Family relationships	p760	10
	Enjoying cuddling, depending on husband for repairing and renovating the house	Intimate relationships	p770	4
	Losing work due to lack of adjustments	Acquiring, keeping and terminating a job	p845	1
	Carrying and griping tools, walking down stairs, continuing to work in	Remunerative employment	p850	4

	the woods, feeding animals			
	Forced to decrease work time to 50%	Economic self-sufficiency	p870	1
	Playing golf, visiting a late cinema show, riding, saddling and fastening the saddle-girth, doing physical exercise, going dancing, going fishing, wearing ski boots and skiing downhill, playing soccer with grandchildren	Recreation and leisure	p920	9
<b>Insufficiency</b>	Shopping and carrying grocery bags	Acquisition of goods and services	p620	1
	Cooking meals	Preparing meals	p630	1
	Staying in a sitting position	Informal social relationships	p750	1
	Enjoying cuddling	Intimate relationships	p770	1
	Handling screws and tools, walking home from work	Remunerative employment	p850	2
	Lacking contact with colleagues when on sick leave	Economic self-sufficiency	p870	1
				47

Table 4 - Feelings of fear as described in relation to participation restrictions of RA from interviews, Sweden 2009-2010.

<b>Feelings of fear</b>	<b>Experienced dilemma</b>	<b>ICF description</b>	<b>ICF code</b>	<b>Number of dilemmas</b>
<b><i>Illness fear</i></b>	Sleeping problems	Maintaining a body position	p415	1
	Opening bottles	Hand and arm use	p445	1
	Take care one's health	Looking after one's health	p570	1
	Getting worse	Doing	p640	2

		housework		
	Raking leaves	Caring for household objects	p650	1
	Taking care of others	Assisting others	p660	1
	Handshaking	Basic interpersonal interactions	p710	2
	Catching colds	Family relationships	p760	1
	Sex and intimacy	Intimate relationships	p770	2
	Disclosure of RA, losing work capacity	Acquiring, keeping and terminating a job	p845	4
		Remunerative employment	p850	6
		Economic self-sufficiency	p870	4
	Continuing voluntary work	Community life	p910	1
<b><i>Fumble fear</i></b>	Walking the dog, wearing high heels, visiting arenas, losing companionship	Recreation and leisure	p920	4
	Shopping	Walking	p450	1
		Acquisition of goods and services	p620	1
	Shoveling, carrying, and taking care of horses	Caring for household objects	p650	2
	Carrying and hugging, playing with grandchildren	Family relationships	p760	2

	Handling work tasks	Remunerative employment	p850	2
	Engaging in after-work activities, walking with friends, fishing, handling gym weights, bathing in adventure pool	Recreation and leisure	p920	5
				44

Table 5 - Feelings of aggressiveness described in relation to participation restrictions of RA from interviews, Sweden 2009-2010.

Feelings of aggressiveness	Experienced RA dilemma	ICF description	ICF code	Number of dilemmas
<i>Anger</i>	Receiving contradictory information from professionals	Handling stress and other psychological demands	p240	1
	Opening bottles	Hand and arm use	p445	1
	Using slippers not shoes	Dressing	p540	1
	Standing up, peeling potatoes	Preparing meals	p630	2
	Gardening, using a spade, threading a needle	Caring for household objects	p650	3

	Helping out family	Family relationships	p760	2
	Enjoying sex and intimacy	Intimate relationships	p770	1
	Experiencing obstacles in continuing work	Acquiring, keeping and terminating a job	p845	2
	Walking with social service clients	Remunerative employment	p850	1
	Signing withdrawal forms, refused money at the bank	Basic economic transactions	p860	1
	Playing musical instruments, arranging flowers, wearing downhill skiing-boots	Recreation and leisure	p920	3
<b><i>Irritability</i></b>	Sleeping, sleeping position	Carrying out daily routine and maintaining a body position	p230 p415	2
	Opening doors, griping tools	Fine hand use	p440	2
	Walking up/down stairs, going by bus	Moving around and using transportation	p455 p470	2
	Going shopping, carrying goods	Acquisition of goods and services	p620	2
	Cleaning the house, taking care of horses	Doing housework and caring for household objects	p640 p650	2
	Playing with grandchildren, watching TV with the family, withdrawing from socializing	Family relationships and recreation and leisure	p760 p920	3
	Enjoying cuddling	Intimate relationships	p770	1
	Losing a job due to lack of adjustments	Acquiring, keeping and terminating a job	p845	1
	Continuing voluntary work	Community life	p910	2
				35

Table 6 - Feelings of shame in relation to participation restrictions of RA from interviews, Sweden 2009-2010.

<b>Feelings of shame</b>	<b>Experienced RA dilemma</b>	<b>ICF description</b>	<b>ICF code</b>	<b>Number of dilemmas</b>
<b><i>Embarrassment</i></b>	Getting out of bed, visiting WC in public	Toileting	p530	2
	Dressing myself with buttons and zippers	Dressing	p540	1
	Restore and repairing the house	Caring for household objects	p650	1
	Carrying my children, caring for two children at the same time	Assisting others	p660	2
	Standing up directly after sitting	Complex interpersonal interactions	p720	1
	Jogging with friends	Informal social relationships	p750	1
	Difficulty driving the car and changing gears makes it hard to visit people, can't help out so avoid visiting relatives and children	Family relationships	p760	2
	Revealing the RA diagnosis	Acquiring, keeping and terminating a job	p845	1
	Limping in front of colleagues, handling money at the sales counter	Remunerative employment	p850	2
	Arranging flowers, doing physical exercise	Recreation and leisure	p920	2
<b><i>Feelings of exclusion</i></b>	Feeling different, can't open cans and bottles at breakfast	Eating	p550	1
	Taking long walks with the dog and the stroller	Caring for household objects	p650	1
	Standing up directly after sitting	Complex interpersonal interactions	p720	1
	Carrying, walking up/down stairs and increasing work-rate,	Remunerative employment	p850	3

	moving old people in and out of bed			
	Unable to receive sickness benefits and make a living	Economic self-sufficiency	p870	1
	Wearing high heels, wearing ski boots, having enough leg space and getting out of the seat in public places, withdrawing from socializing, going on a cruise	Recreation and leisure	p920	6
				28