

RESEARCH ARTICLE

Future Expectations and Worst-Case Future Scenarios of Patients with Rheumatoid Arthritis: A Focus Group Study

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Abstract

Objective. Over the past 15 years, developments in the treatment of rheumatoid arthritis (RA) have resulted in better clinical outcomes. The aim of the present study was to explore how patients think their RA will influence their lives in the future, and which of these future expectations would be the worst for them to experience.

Methods. A focus group study was performed in 16 RA patients. Three groups were heterogeneously composed, based on age group (18–40, 40–65, 65–80), gender and having a paid job or not. Patients were asked about the expected future impact of RA and worst-case future scenarios. Transcripts were coded by three researchers under the main components of the International Classification of Functioning, Disability and Health. The codes were discussed until agreement was reached about all codes.

Results. Dependency on others, increasing dependency on medication, inability to walk, activity limitations and worsening fatigue were mentioned as worst-case future scenarios. Further concerns were raised about the acceptance of RA and possible disappearance of physicians' expertise. Nevertheless, hope and positive feelings were expressed toward continuous medication improvements.

Conclusion. The present study provided insight into RA patients' future expectations and worst-case future scenarios. The results may be of help in the development of support interventions to put concerns and worst-case future scenarios into a realistic perspective. Furthermore, insight into patients' worst-case future scenarios could be used to improve the validity and responsiveness of the Time Trade-Off, an instrument to measure preference-based health-related quality of life. Copyright © 2012 John Wiley & Sons, Ltd.

Keywords

Future expectations; worst-case future scenarios; focus groups; rheumatoid arthritis

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Introduction

Rheumatoid arthritis (RA) is a chronic inflammatory disease characterized by symmetrical, erosive polyarthritis. As a result of advances in treatment and treatment strategies that control disease activity and delay radiological damage (Vermeer et al., 2011; Villeneuve and Emery,

2009), patients experience a reduction in symptoms such as fatigue and an increase in well-being, which are more important outcomes to them than traditional outcomes such as joint swelling and stiffness (Hewlett et al., 2005).

In light of the continuous treatment innovations that provide considerable benefits to patients' health, it is

interesting to examine how RA patients think their disease will influence their future lives (i.e. future expectations related to RA), and which of these future expectations would be the worst for them to experience (i.e. worst-case future scenarios). This insight can reveal whether patients' expectations and worst-case future scenarios related to their RA are realistic and can help in the development of support interventions to put these into a realistic perspective and to help patients in coping with fears and concerns, in order to improve their health-related quality of life (HRQoL).

Knowing patients' worst-case future scenarios can also be valuable for the measurement of preference-based HRQoL. The Time Trade-Off (TTO) instrument (Torrance et al., 1972) measures patients' valuations of their own health state (patients' utilities) by asking the number of life years that patients are willing to trade for perfect health (i.e. to avoid being in their current health state). Thus, patients have to compare their current health state with the anchor state 'death'. In this way, an estimation of the severity of the current health state is obtained. It is assumed that the more life years patients are willing to trade off, the worse their health state is. However, 'dying earlier' may not be perceived by RA patients as a realistic consequence of their disease. It is possible that replacing the anchor 'death' by a worst-case anchor that is perceived by RA patients as a realistic consequence of RA improves the validity and responsiveness of this instrument.

The first aim of the present study was to examine RA patients' future expectations. The second aim was to reveal worst-case future scenarios.

Methods

Patients and study design

RA patients were recruited consecutively from the outpatient rheumatology clinic of a Dutch hospital in February 2009. Three heterogeneous focus groups of six patients each were composed, based on age group (18–40, 40–65, 65–80), gender and having a paid job or not, in order to enhance discussion (Barbour, 2005). A semi-structured question format was used. The discussion was conducted by a moderator (L.B.). A note-taker (A.B.) was present. Every session took about an hour and a half. Data saturation was checked afterwards to determine the desirability of organizing additional groups. The conversations were recorded and transcribed verbatim.

Measures

The focus group sessions comprised two subjects: expectations about the future influence of RA (questions: *How do you envisage yourself living with rheumatism in the future and in what way do you think that your rheumatism will influence your life in the future?*) and worst-case future scenarios derived from these future expectations (questions: *Of all the expectations that have been listed so far, which one would you consider to be the worst? What are you most afraid of?*). In case of non- or limited response, or in order to clarify responses, sub-questions were asked. The focus group schedule and the questions were constructed by three researchers (L.B., A.B., E.T.). All questions are shown in Appendix 1. To ensure that we did not miss out any worst-case future scenario mentioned, the note-taker wrote down all scenarios on cards. Subsequently, participants were asked to indicate if any scenario was missing or if scenarios belonged together.

Analysis

The conversations were individually coded and interpreted by three researchers (L.B., A.B., E.T.). The World Health Organization International Classification of Functioning, Disability and Health (ICF) (World Health Organization, 2001) was used to categorize the coded expressions. To clarify the content of the expressions in a logical manner, the expressions were categorized under the main components of the ICF (body functions and structures, activities and participation, environmental factors and personal factors). The first, second, third and fourth level categories were not described. We categorized the objects of the expressions. To clarify this: when a participant expressed concerns about *the ability to walk* in the future, we did not categorize this worry as a personal factor, but we linked the object of this concern (italicized) to the ICF main component 'activities and participation'. The codes were discussed (by L.B., A.B. and E.T.) until agreement was reached about all codes.

Ethical approval

According to local regulations in the Netherlands (WMO), no approval of the ethical review board was needed. Only (non-intervention) studies with a high burden for patients have to be reviewed. Patients underwent no intervention or treatment, and the burden of participation was relatively low.

Results

The demographic and clinical characteristics of the 16 participating RA patients are shown in Table 1. Data saturation was achieved sufficiently. An overview of participants' future expectations linked to the ICF domains is shown in Table 2.

Body functions and structures

Fatigue was a prevailing, uncontrollable problem. Only two participants reported future concerns about *worsening fatigue*. For example:

'...And then I think to myself... if this should get any worse, all I am doing is going to work, coming home, eating and throwing in the towel, that's it really...' (woman, 56 years, RA for 19 years).

Many participants experienced *side effects of medication* or had experienced these in the past, which they hoped not to face again. Uncertainties and fears were expressed concerning side effects:

'I think I'm on quite a lot of different medicine at the moment, so I really think, couldn't these be less? How long can my stomach and the rest of me put up with all of this?' (woman, 70 years, RA for three years).

'In fact, the very thought terrifies me. All those stomach troubles and the internal bleeding. It's no picnic if you are sitting on the toilet at night and you suddenly see a whole mass of blood' (man, 73 years, RA for 37 years).

One participant expected to have a *reduced life expectancy* because of the medication she had to take. Nevertheless, the reduced life expectancy did not outweigh the benefits of the medication:

'It's common knowledge that when you're given medication for your rheumatism your life expectancy will probably decrease, and be a bit shorter. At least, that's what I read all over the place. I do take it on board, also with regard to the medicines, but I put it into context by thinking: what is the average life expectancy anyway? How old am I now? And what are the risks of this actually happening to me?' (woman, 72 years, RA for two years).

Participants did not mention any future concerns regarding *pain*. Participants experienced pain, but most people compared their current pain level with the level at diagnosis, and indicated that the pain had decreased tremendously. One participant explicitly stated that it would not be a problem if the pain worsened. Participants indicated that they got used to the pain; that they had to cope with it. For example:

Table 1. Demographic and clinical characteristics of the 16 participants in the three focus groups

Focus group	Participant	Age (years)	Gender	Marital status	Educational level	Work status	Disease duration (years)
1	1	55	Female	Single	Moderate	Paid work	5
	2	56	Female	Single	High	Paid work	19
	3	70	Female	Married	Low	Retired	3
	4	49	Male	Married	Moderate	Paid work	5
	5	62	Male	Married	Moderate	Paid work	7
2	1	60	Male	Married	High	Unemployed	19
	2	59	Female	Married	Low	Housekeeper	1
	3	68	Female	Single	Low	Retired	24
	4	60	Male	Married	Low	Paid work	4
	5	52	Female	Married	Moderate	Unemployed	1
	6	72	Male	Single	Low	Retired	37
3	1	72	Male	Single	High	Retired	24
	2	59	Male	Married	Low	Paid work	6
	3	68	Female	Married	High	Retired	39
	4	41	Female	Living together	High	Paid work	10
	5	72	Female	Living together	High	Retired	2

Table 2. Future expectations and worst-case future scenarios categorized under the ICF

ICF category	Future expectations	Worst-case future scenarios
Body functions and structures	Expected decrease in life expectancy owing to medication Concerns about worsening fatigue Concerns about side effects of medication	Worsening fatigue
Activities and participation	Expected decrease in activity performance as a result of ageing Concerns about dependency on others Concerns about activity limitations Concerns about ability to walk	Dependency on others Inability to perform hobbies Inability to walk
Environmental factors	Expected disappearance of expertise as a result of better career perspectives for physicians elsewhere Concerns about increasing dependency on medication Positive feelings and hope of continuously improved medication	Increasing dependency on medication
Personal factors	Concerns about maintaining the ability to accept the disease	

ICF, International Classification of Functioning, Disability and Health.

'With the pain being like it is now. . . well . . . even if it becomes worse. . . no, that is not such a problem, no. If you compare it to what it was like when I first got it. . .' (man, 62 years, RA for seven years).

'Now, almost none [pain], occasionally. You just get used to it, of course.' (woman, 68 years, RA for 24 years).

'You have to live with that. . .or you go under to it. . .' (woman, 70 years, RA for three years).

Activities and participation

Many participants expressed concerns about *becoming dependent on others*. They felt that being unable to be independent and needing help from others regarding all kind of activities would be hard to take. For example:

' . . .that you still have a little bit of independence and that you can still do things more or less . . . such as small errands to the shops' (woman, 70 years, RA for three years).

In one focus group, concerns were particularly raised about self-care because of the intimacy of activities related to it. For example:

' . . .that I'll be dependent on my husband or children. . . I hope that it never gets to that stage, that would be terrible for me. . . And this is what terrifies me. . . I always had to help my mother to wash

herself and to have a shower and I don't know how many other things: no, it is not pleasant' (woman, 59 years, RA for one year).

Many participants expressed uncertainties and fears about *activity limitations*, such as limitations in hobbies, driving or shopping. For example:

'If I start to focus on the future, then I sometimes feel anxious.'

Interviewer:

'And what are you afraid of exactly?'

Participant:

'That you can no longer do the things that you do now. . . Playing the guitar, for one. I'm really anxious about this. It is not work-related, it's just a hobby, but I really love it. If I am not able to play anymore. . .' (man, 49 years, RA for five years).

One participant anticipated the possibility of reduced capacities:

' . . .I always fancied being an artist. . . I cancelled all my managerial positions a few years ago and that's when I began to paint . . . I think to myself, if it gets to the point where I cannot do it anymore, then at least I will have a couple of my own paintings hanging on the wall' (man, 59, RA for six years).

The process of *ageing* was seen as an important factor for influencing future capabilities:

'I think that it might deteriorate a bit further. . . but that probably has a lot to do with one's age as well. So in that sense you're never be as fit as you used to be years ago anyway' (woman, 55 years, RA for five years).

Losing independence and having limitations in the ability to perform activities are intertwined: the inability to perform activities leads inevitably to the need for assistance from others:

'Yes, that you can still drive a car and that you're still a bit independent and that you can manage to do everything to a certain point. . . like errands and shopping and you know pretty well that you can't fill a shopping trolley and push it around, but still manage to do a bit' (woman, 70 years, RA for three years).

One person emphasized her concerns about the *ability to walk*: although dependency would be terrible, the inability to walk was regarded as a tremendous, unimaginable, limitation:

'I think that I would have this too, that I would find it terrible if I couldn't walk anymore. Then of course you would be dependent on others, but I find it hard to imagine how it would be to be unable to walk . . . there are support aids available, but that's not the point, the very thought that you cannot get into a car by yourself or jump on a bike, then you're completely stuck. That is a major hindrance of course' (woman, 68 years, RA for 39 years).

Environmental factors

One participant especially expressed concerns about becoming *increasingly dependent on medication*:

'Being dependent on medication: that's what I find terrible. The idea that you cannot live without taking the medicines. And that the amount will steadily increase. It begins with a cure for rheumatism, then something for the stomach complaints is added, and something for brittle bones, and before I knew it I was up to nine a day. Simply to counteract the side effects of the medicines a little. There's no end to it. . . That's what worries me the most' (man, 72 years, RA for 24 years).

Positive feelings and hopes about *future improvements in medication* were expressed, also because of previous experiences. For example:

'Then if you are told, this is the last available treatment . . . but in the meantime, new medicines appear . . . and it will continue. . . and then I'll improve again. . . and this has all happened in the last few years . . . of course there are all sorts of side effects, but you know that something else will be made available after that' (woman, 56 years, RA for 19 years).

Nevertheless, concerns were reflected in many expressions of hope. For example:

'I was 45 when I got rheumatism and my children were still young. At the time, I sometimes found myself thinking: goodness, how am I going to manage? But just keep taking the medicine and hope that better medicines will become available, because – as I say – you have to stay hopeful' (woman, 68 years, RA for 24 years).

One participant expressed the fear of *disappearing expertise* because of better career perspectives for physicians elsewhere:

'The thing that worries me is. . . how long will it be before the doctors are dragged away to fill some academic position elsewhere? I have the feeling that we have brilliant doctors and specialists working here who will sooner or later say goodbye' (woman, 72 years, RA for two years).

Personal factors

One participant hoped to *keep the ability to accept the disease* and to enjoy life:

'I hope that I can continue to accept the fact that it's there and focus on enjoying what we still can do. Because if you lose sight of that, then you're truly lost' (woman, 70 years, RA for three years).

Worst-case future scenarios

Of the future expectations listed, *being dependent on others* would be the worst 'fear' for the future for most participants. Not being able to function independently, but needing the assistance of others would be a great

burden to them. In one focus group, dependency was particularly related to activities of *self-care*, such as showering and going to the toilet. Some participants expected to get used to it eventually. Uncertainty about the actual reaction when facing dependency was also raised. For example:

'I haven't given it much thought yet. But I can imagine that also for myself; that for me would be the worst thing too. Being washed by strangers. Maybe one gets used to it... I'd find it difficult the first three times and will become really nervous about it half an hour beforehand, but after two or three times one would get used to it, at least I hope so... It is true, it's hard to say in advance how you would actually deal with everything that will cross your path. You don't know yourself yet, you just don't know how you would cope or react in that particular situation' (man, 60 years, RA for 19 years).

For one participant an *increasing dependency on medication* was worrying and would be the worst-case future scenario. The inability to live without medication and the inevitability of accumulating medication worried him. For two participants, *losing the ability to walk* would be the worst thing they could experience in the future, for another it was the *inability to perform hobbies*, and for another it was *worsening fatigue*:

'I'm more bothered by the fact that the feeling of tiredness doesn't go away. Sometimes I think to myself, good grief: there I go – I have got to sit down again. That's indeed my biggest bug-bear. I hope that doesn't get worse' (woman, 55 years, RA for five years).

Discussion

The present focus group study in RA patients revealed diverse future expectations related to all ICF categories. Regarding worst-case future scenarios, dependency on others, worsening fatigue, inability to perform hobbies, the inability to walk and increasing dependency on medication were mentioned.

Remarkably, patients did not report any concern about the pain they experienced. Pain was not much of a problem for them. Either they compared their current pain level with the level at diagnosis, or they indicated that they got used to the pain. By contrast, a

semi-structured interview study in RA patients (Taal et al., 1993) showed that pain was considered to be a main problem of the disease and was seen as problematic by the majority of participants (86%). Furthermore, a semi-structured interview study about RA patients' concerns revealed worries about increasing pain in the future (Bath et al., 1999). It is likely that this difference can be explained by the fact that treatment strategies for RA have improved tremendously over the past decade.

Previous studies (Hewlett et al., 2005; Melanson and Downe-Wamboldt, 2003; Taal et al., 1993; van Lankveld et al., 1993) have already demonstrated that dependency on others is a major problem for RA patients. The results of the present study regarding patients' concerns were consistent with those of other studies (Bath et al., 1999; Lempp et al., 2006; Lütze and Archenholtz, 2007) with respect to concerns about losing independence and becoming a burden to others. Moreover, consistent with the present study, a previous study reported concerns about the inability to perform daily activities (Bath et al., 1999), and a more recent study about fatigue (Repping-Wuts et al., 2009).

Not all expectations and worst-case future scenarios are likely to be realistic from a clinical perspective because of continuous advances in the treatment and management of RA (e.g. the introduction of tumour necrosis factor blockers (Keystone et al., 2004; Klareskog et al., 2004) and treat-to-target strategies (Vermeer et al., 2011)). Nevertheless, from the patients' perspective, these expectations and worst-case scenarios are perceived as realistic.

The present results support the development of interventions that teach patients to cope with their concerns and to put expectations and worst-case future scenarios into a realistic perspective. Furthermore, the results could be used to improve the TTO. Studies applying the TTO have shown that a number of people are reluctant to trade any life years for perfect health. These people are called 'zero-traders' (Arnesen and Trommald, 2005). Because of their unwillingness to trade any life years for perfect health, zero-traders give the impression that their health is perfect, leading to an overestimation of HRQoL. Consequently, the validity and responsiveness of the TTO are limited. An explanation for the existence of zero-traders is that giving up life years (i.e. dying earlier) is not perceived by RA patients as a realistic consequence of RA. This was confirmed in the current study, as dying earlier was not mentioned by most

participants as a future expectation. Replacing the current anchor 'death' by an anchor that is perceived by RA patients as a realistic consequence of RA (e.g. 'dependency on others' or 'inability to walk') could improve the validity and responsiveness of the TTO. Obviously, a larger, quantitative study of RA patients is needed to validate the results.

A limitation of the present study was that participants might have felt inhibited to talk freely because of the group format. Furthermore, social pressure could have affected responses. Nevertheless, the possibility for participants to identify themselves with others sharing similar experiences could have facilitated disclosure (Wong, 2008). Besides, the process of group interaction has the advantage of facilitating participants to clarify and revise their opinions based on the contribution of others (Powell and Single, 1996).

Conclusion

The present study provided insight into RA patients' future expectations and worst-case future scenarios. Regarding worst-case future scenarios, dependency on others, worsening fatigue, inability to perform hobbies, the inability to walk and increasing dependency on medication were mentioned. The results may be of help in the development of support interventions. Furthermore, insight into patients' worst-case future scenarios could improve the validity and responsiveness of the TTO, an instrument for measuring preference-based HRQoL.

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Focus group questions

A. Appendix 1

Main question 1.

How do you envisage yourself living with rheumatism in the future and in what way do you think that your rheumatism will influence your life in the future?

Sub questions. (in case of non- or limited response)

- *Do you envisage your rheumatism getting better or worse in the future? Can you describe this in more detail (in what way will it get better/become worse)?*
-

(Continues)

- *(If everyone expects the rheumatic disease to improve): Just suppose for a moment that it will become worse than you thought; how might your life be influenced by your rheumatism then? How do you think you will handle this?*
- *What kind of influence does rheumatism have on your life now?*
- *Could you name one or two concrete situations in which you noticed this type of influence?*
- *Do you expect that this will continue to be the case in the future? In what way will your rheumatism have an influence on your life in the future?*

Main question 2.

Of all the expectations that have been listed so far, which one would you consider to be the worst? What are you most afraid of?

Sub-questions (to clarify responses)

- *Have these already been mentioned, or not?*
 - *Can you indicate what it is that makes you so afraid? Why are you so afraid of this?*
 - *Are there expectations listed on the board that are named differently, but have the same meaning for you?*
- Is there anything that you feel is missing in this discussion about expectations for the future?*
-