RHEUMATOLOGY

Original article

Worst-case future scenarios of patients with rheumatoid arthritis: a cross-sectional study

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Abstract

Objective. The time trade-off is a health-related quality of life instrument that measures valuations for health states (utilities) by asking patients to value their health state anchored on a scale between death (0) and perfect health (1). Dying earlier is not perceived as a realistic worst-case consequence of the disease by RA patients. Of the previous focus groups study on RA patients, five worst-case future scenarios emerged. The aim of this study was to examine which potential worst-case scenario was the most appropriate for RA patients to use in utility calculation.

Methods. In a cross-sectional study of 74 consecutive RA patients visiting the rheumatology outpatient clinic, participants were presented with descriptions of the five worst-case future scenarios. In pairwise comparisons, patients had to choose the scenario that would be the worst to experience. The worst-case future scenario was defined by the scenario that was chosen by a significantly greater proportion of participants than could be expected based on chance (20%). Therefore, analysis based on a single fraction ($\widehat{P}$) was used and 95% CI was calculated.

Results. The scenario being dependent on others was chosen most often as the worst to experience [by 35% of participants (95% CI 24%, 46%)] and significantly more often than could be expected based on chance ($\widehat{P} = 0.35$, $z = 6.45$, $P = 0.00$).

Conclusion. The scenario being dependent on others is likely to be the most appropriate worst-case future scenario for RA patients. Using an alternative anchor could improve the validity and responsiveness of the time trade-off in RA patients.

Key words: quality of life, patient preference, rheumatoid arthritis.

Introduction

RA is a chronic, autoimmune disease characterized by chronic symmetric polyarthritis. Most patients will have joint destruction, functional impairments and increased mortality [1]. RA can have a great impact on patients' health-related quality of life (HRQoL) [2, 3]. HRQoL can be defined as the extent to which physical, emotional and social well-being are impacted by the medical condition and/or its treatment [3]. Fortunately, in the last century, developments in treatment have improved patients' clinical status dramatically [4, 5] and also patients' HRQoL [6–8].

Various methods have been developed to measure HRQoL; either descriptive or valuation methods can be used. The first type of method is designed to give a detailed description of patients' health states (e.g. SF-36). The second type of method is designed to obtain valuations for patients' health states (utilities). Health states are valued on a scale anchored between death (0) and perfect health (1). Utilities can be obtained directly from patients or indirectly by attaching utility weights of the general public to health states of patients. Direct utility elicitation methods are instruments, such as the standard gamble [9, 10] or time trade-off (TTO) [11].

The TTO is a frequently used method in case of direct utility elicitation. The TTO asks patients about the number of life years they are willing to trade for perfect

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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, studies applying the TTO have shown that people do not always trade life years for perfect health (zero-traders) [12]. A range in the proportions of zero-traders from 1.7% to 58% of participants has been found [12]. Zero-traders can lead to ceiling effects, as they score the highest possible TTO score (1.00). 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 their HRQoL. As a consequence, the validity and responsiveness of the TTO is limited. A possible explanation is that giving up life years, i.e. dying earlier, is not perceived as a realistic consequence of their disease by patients with RA [13]. Furthermore, patients have often adapted to their life with RA and have cognitively integrated the illness into their lives by redefining their internal standards of what comprises health, changing their values and priorities and/or redefining the concept of quality of life. Therefore, perfect health is not seen as an important or realistic goal. Replacing the current anchor death by an anchor that is perceived as a realistic consequence of RA from the perspective of patients may reduce the number of zero-traders, which could improve the validity and responsiveness of the TTO in patients with RA. The TTO utility scales are constructed for use in cost-utility analyses and for assistance in decisions about resource allocation. Changes in the validity, reliability and responsiveness of the utility scales might lead to changes in decisions about resource allocation.

To find alternative anchors for the TTO, we examined RA patients' future expectations and worst-case future scenarios in a previous focus group study [13]. Concerns and worst-case future scenarios were related to dependence on others, worsening fatigue, inability to perform hobbies, inability to walk and increasing dependence on medication. All five worst-case future scenarios that were mentioned in the focus group study were used in the current study.

Before an alternative TTO can be developed, a quantitative study should be performed to validate the results of the focus group study. Therefore, the aim of this study was to examine which of the five worst-case future scenarios that emerged from the focus group study was the most appropriate worst-case future scenario for RA patients to be used as an anchor in the TTO to obtain utilities.

Methods

Patients and study design

Consecutive patients diagnosed with RA (aged 18–75) visiting the rheumatology outpatient clinic of Medisch Spectrum Twente, Enschede, The Netherlands, participated in the study. Patients who could speak and read the Dutch language were handed an information letter and

asked by the attending rheumatologist to participate. Patients who agreed to participate were introduced to the researcher (L.B.) who informed them about the study in more detail. The study was done within 2–4 weeks thereafter.

After informed consent was obtained, patients had to choose in pairwise comparisons the scenario that would be the worst to experience. Subsequently, they had to complete questionnaires about their current experience with the five worst-case future scenarios, about sociodemographic information, pain (numerical rating scale), functional status (HAQ consensus) and quality of life (SF-36: mental and physical component scales). The researcher was present (L.B.) to introduce the questionnaires. The study was approved by the Central Committee on Research Involving Human Subjects.

Measures

Pilot study
Previous to this study, a pilot study was conducted to assess whether the scenarios were conceivable, clear and comprehensive. One adaptation was made. The scenario that was labelled as no longer able to do any hobbies was renamed as no longer able to do any leisure activities in your free time. Participants remarked that the term hobbies inclined them to only think about specific activities like handicraft or collecting items, rather than about any activity that they might want to do in their free time.

Study
Worst-case future scenarios. Participants were presented with descriptions of the five worst-case future scenarios. In pairwise comparisons, they were asked to choose the scenario that would be the worst to experience. Each scenario was compared with all the other scenarios, resulting in 10 comparisons. An opt-out option allowed participants to indicate that they would not choose any scenario from the pair. Four random versions of the 10 comparisons were designed to rule out possible sequence effects. By means of a computer, four random sequences of the numbers 1–10 were obtained. In advance, participants were assigned to one of the four versions by using blockwise randomization. The five scenarios were being dependent on others, being extremely fatigued, being unable to perform leisure activities anymore, being unable to walk anymore and being dependent on medication.

Current experience of worst-case future scenarios. In five questions, participants had to indicate on a numerical scale from 0 (not experienced) to 10 (fully experienced) the extent to which they currently experienced being in the state as described in the five worst-case future scenarios.

Pain. Current severity of the pain was assessed by a numerical rating scale (NRS), ranging from 0 (best) to 10 (worst).

Functional status. The level of functional disability was assessed by the Dutch consensus HAQ (HAQ consensus) [14] based on the HAQ Disability Index (HAQ-DI) [15], a self-report measure consisting of eight categories (dressing and grooming, rising, eating, walking, hygiene, reach, grip and common daily activities). The HAQ-DI score ranges from 0 to 3, with higher scores indicating lower levels of functioning. The HAQ-DI has been proved valid [16, 17].

HRQoL (physical and mental health). Physical and mental health were assessed by calculating the physical component summary (PCS) and mental component summary (MCS) scores of the SF-36 version 2 [18, 19], a generic descriptive instrument for measuring HRQoL on eight dimensions (mental functioning, physical functioning, bodily pain, vitality, role limitations because of physical problems, role limitations because of emotional problems, social functioning and general health). Evidence for the validity of the PCS and MCS of the SF-36 in RA patients has been found [20]. The PCS and MCS scores range from 0 to 100, whereby a higher score indicates a better health.

Statistical analysis

Although our study has an explorative character, we performed a power analysis based on the main objective of the study. Using an alpha of 0.05 (two-tailed) and a power $(1 - \beta)$ of 80%, a sample of 72 participants is required to detect a difference of 15% between the proportion of participants who chose a certain scenario most often as the worst to experience and the proportion based on chance (expected proportion based on chance is 20%).

To calculate which of the five scenarios (A, B, C, D and E) was chosen most often as the worst to experience, a ranking of scenarios was calculated based on the 10 comparisons (AB, AC, AD, AE, BC, BD, BE, CD, CE and DE). Each scenario was compared with the other four scenarios. In each comparison, the scenario that was chosen as the worst to experience was given 1 point, the other scenario was given 0 points. Adding up the points for each scenario resulted in a score for each scenario ranging from 0 (never chosen as the worst to experience) to 4 (in all comparisons chosen as the worst to experience). The scenario with the highest score was considered to be the worst-case future scenario for the participant. If participants turned out to have two or more scenarios equally ranked as the worst to experience, we considered their answer on the comparisons of these equally ranked scenarios as their worst-case future scenario. The worst-case future scenario was defined by the scenario that was chosen by a significantly greater proportion of participants than could be expected based on chance (20%). Therefore, analysis based on a single fraction $(\widehat{P})$ was used. Furthermore, 95% CI for proportions were calculated.

In addition, it was examined whether the results of the single fraction analysis changed when participants who already experienced one or more of these states were left out of the analysis. Participants who scored >8 on

the question whether they currently experienced a certain state as described in the scenarios were considered to experience that state.

Furthermore, it was examined for the scenario that was chosen most often as the worst to experience, whether there were also participants who did not choose this scenario to be worse than any of the other scenarios. Data were analysed using PASW Statistics (version 18; SPSS, Inc., Chicago, IL, USA).

Results

Subjects

Of the 84 participants who agreed to participate, 74 participants eventually participated. No significant differences in gender, disease activity and general health (NRS general health) were found between the included participants ($n = 74$) and the non-included participants ($n = 10$). A significant difference in age was found ($U = 185.00$, $z = -2.56$, $P < 0.01$) between the included participants {median age [interquartile range (IQR)] = 58 (52.42–66.08)} and non-included participants [median age (IQR) = 68 (64.12–72.46)]. Demographic and clinical characteristics of the 74 participants are reported in Table 1.

Worst-case future scenario

The worst-case future scenarios are shown in Fig. 1. The total number of comparisons that participants completed was 740. In 53 of these comparisons (7.2%), no choice was made.

The scenario being dependent on others was chosen most often as the worst to experience by 35% of participants (95% CI 24%, 46%). This percentage was significantly higher than could be expected based on chance ($\widehat{P} = 0.35$, $z = 3.26$, $P = 0.00$). The percentages of the latter four scenarios did not significantly deviate from chance (Table 2).

Median (IQR) scores regarding the experience of the scenarios are shown in Table 1. Interestingly, being dependent on others is less frequently experienced than the other four scenarios. Twelve participants (16%) experienced one or more of the worse states (experience score >8) (Table 1). For the remaining 62 participants who did not experience any of the states described in the scenarios (experience score ≤8), the scenario being dependent on others was still chosen most often as the worst to experience (Table 2). The percentages of the other four scenarios did not significantly deviate from chance. Four participants (5.4% of the 74 participants) did not choose the scenario being dependent on others as the worst to experience in any of the 10 comparisons.

Discussion

This study of RA patients revealed that the scenario being dependent on others was most often indicated as the worst to experience. Moreover, it was the only scenario that was indicated significantly more often as the worst to experience than could be expected based on chance;

TABLE 1 Personal and disease-related characteristics of the 74 participants

	Total group (n = 74)
Mean age (S.D.)	58 (8)
Gender, %	
Men	38
Women	62
Marital status, %	
Single	16
Married/living together	84
Educational level, %	
Low	59
Moderate	23
High	18
Work status, %	
Paid work	44
Housekeeping	14
Retired/unemployed/disabled	42
Medication, %	
DMARD	70
Biologic	30
Median disease duration (IQR), years	7.00 (3.75–13.00)
Mean disease activity (S.D.) (DAS28 1–10)	2.47 (1.02)
Median pain (IQR) (NRS)	3.00 (2.00–5.00)
Median HAQ-DI (IQR)	0.50 (0.14–1.00)
Mean physical health (S.D.) (PCS)	42.39 (8.59)
Mean mental health (S.D.) (MCS)	50.97 (10.85)
Median experience of being dependent on others (IQR) (0–10)[a]	2.00 (0.00–4.00)
Median experience of being dependent on medication (IQR)[a]	5.00 (3.00–8.00)
Median experience of being extremely fatigued (IQR)[a]	4.00 (2.00–6.00)
Median experience of no longer being able to do any leisure activities in the free time (IQR)[a]	3.00 (1.00–5.00)
Median experience of no longer being able to walk (IQR)[a]	3.00 (1.00–5.00)
Participants (n) being in one or more of the worst health states (current experience >8), %	12 (16)

[a]A score of 0: the scenario has not (yet) been experienced; a score of 10: the scenario has been fully experienced as it has been described. DAS28: disease activity score in 28 joints.

even after repeating the analysis without patients who already experienced one or more of the worst states.

Although this study is the first to reveal RA patients' worst-case future scenarios, previous studies [21–24] have already demonstrated that dependency on others is one of the most important problems for RA patients, except for the study of Gossec *et al.* [25] that did not show that this was one of the most important health outcomes for RA patients. Functional limitations, mobility and fatigue were also mentioned within the top three of most important problems or outcomes, although not all these studies mentioned each of them. All these studies did have pain among the top three of most important

problems or outcomes. Remarkably, in our previous focus group study, pain was not considered to be a worst-case future scenario, and therefore, we did not include pain in this study. A possible explanation is that we asked for future scenarios, whereas the previous studies asked for current problems or outcomes. Furthermore, in the focus groups some patients stated that they experienced pain, but compared their pain levels with pain levels at the time of diagnosis and indicated that the pain had decreased tremendously. Also, participants indicated that they got used to the pain; that they had to cope with it. This may also explain why they did not mention pain as a worst-case future scenario.
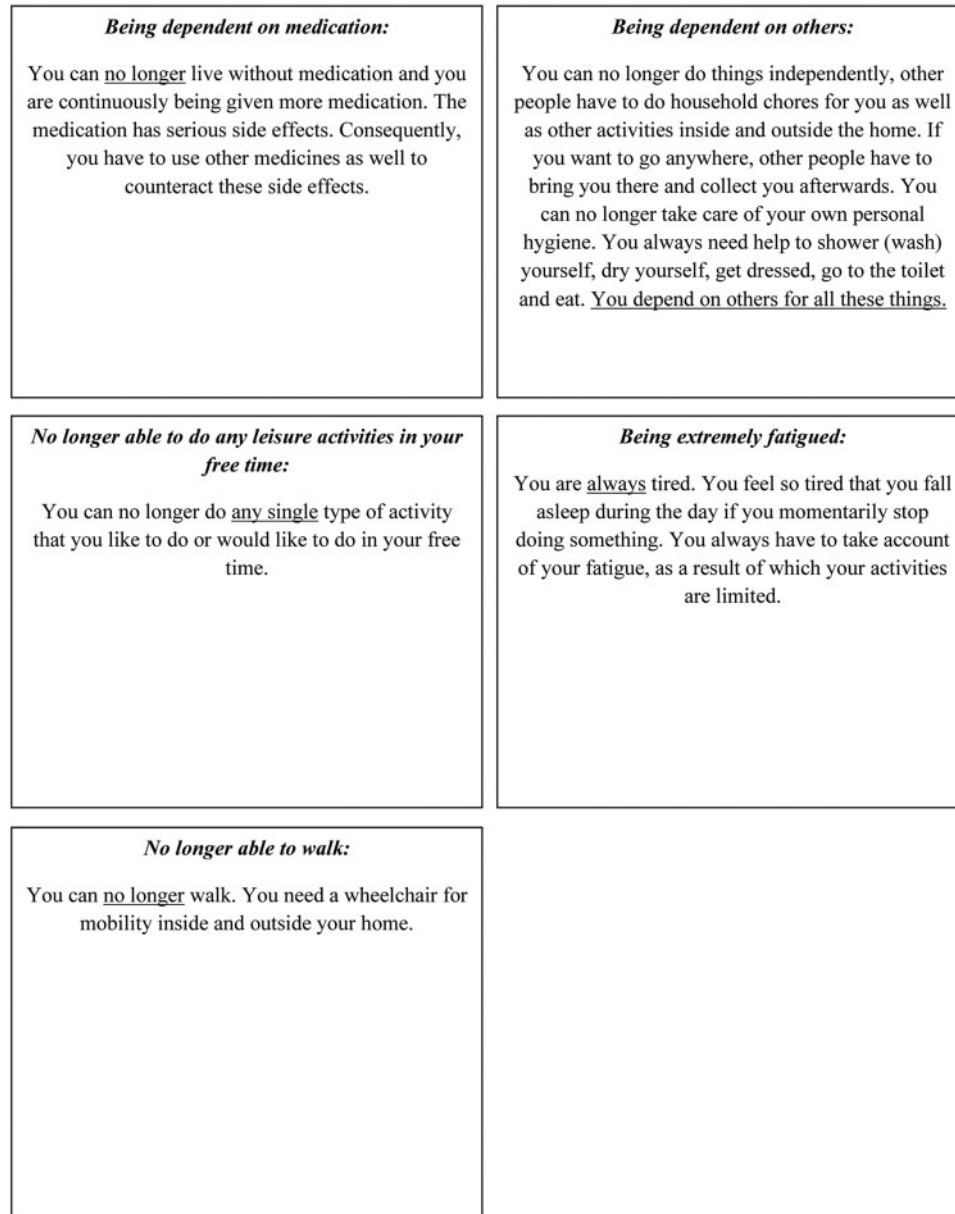
When applying the scenario being dependent on others as a new anchor in the TTO, patients would be asked how many years in dependency they are willing to make a trade-off to become perfectly healthy. Therefore, people have to choose between a life in their current health state and a life in a better health state for a shorter number of years (being perfectly healthy) followed by a number of years in the worse health state (being dependent on others).

This study showed that none of the participants experienced this worst state of being dependent on others. Being in a state that is used in the trade of the TTO will bias the utility score downward, leading to floor effects that produce an underestimation in HRQoL; it is expected that these participants are, irrespective of their current health, willing to accept no years in perfect health, and thus, all years in a state they already experience. This will result in a utility score of 0, indicating a very bad current health state. However, as no participants have indicated to be in the state of being dependent on others, downward biases are not likely when being dependent on others is used as an anchor in the TTO.

Some participants in our study (5.4%) did not choose the scenario being dependent on others as the worst to experience in any of the 10 comparisons. For these participants, the sensitivity of a TTO with being dependent as an anchor state may be decreased; the utility score may be biased downwards.

Interestingly, the scenario being dependent on others was experienced least, although it was most often chosen as the worst to experience. It seems that patients who do not have much experience with a state find this state the worst to experience. This explanation is supported by research that has examined differences in values of health states between patients and members of the general public. Patients have been found to assign higher values to their health states than people of the general public who generally do not have any experience with these health states [26–28]. Furthermore, research has shown that patients assign lower utility scores to states they do not experience than to states they do experience [29]. Therefore, states that have not been experienced (hypothetical states) are worse for people than states that have been experienced. An explanation is that people undervalue their own ability to adapt [30, 31].

FIG. 1 Descriptions of the five worst-case future scenarios.

Being dependent on medication:

You can no longer live without medication and you are continuously being given more medication. The medication has serious side effects. Consequently, you have to use other medicines as well to counteract these side effects.

Being dependent on others:

You can no longer do things independently, other people have to do household chores for you as well as other activities inside and outside the home. If you want to go anywhere, other people have to bring you there and collect you afterwards. You can no longer take care of your own personal hygiene. You always need help to shower (wash) yourself, dry yourself, get dressed, go to the toilet and eat. You depend on others for all these things.

No longer able to do any leisure activities in your free time:

You can no longer do any single type of activity that you like to do or would like to do in your free time.

Being extremely fatigued:

You are always tired. You feel so tired that you fall asleep during the day if you momentarily stop doing something. You always have to take account of your fatigue, as a result of which your activities are limited.

No longer able to walk:

You can no longer walk. You need a wheelchair for mobility inside and outside your home.

When an adapted TTO with being dependent on others as the anchor state turns out to enhance the validity and responsiveness of the TTO, it could be used, for instance, to measure the effects of treatments at the group level from a patient perspective to determine the optimal treatment for groups of RA patients.

It has to be remarked that, although the scenario being dependent on others was chosen most often as the worst to experience by RA patients, 65% of participants had not chosen this scenario most often as the worst to experience. The other four scenarios were also chosen by 12–18% of the participants as worst to experience. In addition, 12% of participants were indifferent. Other studies also showed that, although dependency on others

was one of the most important problems for RA patients, it was not selected by the majority of patients in the top three of most important outcomes [21, 22]. Hewlett *et al.* [21] concluded from this finding that no outcome is universally important. For patients who do not consider being dependent on others as their worst-case future scenario, the use of it as an anchor in the TTO can be problematic. Therefore, the scenario should be compared with the current scenario death to examine how much of a problem this is. Nevertheless, it should also be noted that even when dying earlier turns out to be the worst-case future scenario for RA patients, it is probably not perceived as a realistic consequence of RA, as it was not mentioned in the focus group study to be a concern and/or worst-case

TABLE 2 Percentage of participants divided over every worst-case future scenario and significance tests for all participants ($n = 74$) and for the participants ($n = 62$) who were not considered to be in the worst state (experience score $\leqslant 8$)

	Percentage of participants (95% CI) ($n = 74$)	P [significantly different from chance (20%)]	Percentage of participants (95% CI) (experience score $\leqslant 8$) ($n = 62$)	P [significantly different from chance (20%)] (experience score $\leqslant 8$)
Being dependent on others	35 (24, 46)	0.00	37 (25, 49)	0.01
No longer being able to walk	18 (9, 27)	0.61	15 (6, 24)	0.28
Being dependent on medication	12 (5, 19)	0.09	11 (3, 19)	0.09
No longer being able to do any leisure activities in your free time	11 (4, 18)	0.05	11 (3, 19)	0.09
Being extremely fatigued	12 (5, 19)	0.09	13 (5, 21)	0.16
Being indifferent	12 (5, 19)		13 (5, 21)	

future scenario. The sample of RA patients used in this study seems to be a representative sample of the Dutch RA population in usual care. The short disease duration, low disease activity scores (DAS28) and low pain scores found in our sample were comparable with the clinical characteristics of a Dutch sample of consecutive patients seen in standard rheumatology care that was part of the Quantitative Patient Questionnaires in Standard Monitoring of Patients with Rheumatoid Arthritis (QUEST-RA) study [32].

This study is the first to reveal that being dependent on others was the worst-case future scenario for RA patients. A further step is to examine the psychometric properties of the TTO with being dependent on others as an alternative to the current anchor, death.

Rheumatology key messages

- The current TTO anchor dying earlier is not perceived as a realistic RA-related consequence.
- RA patients' worst-case future scenarios could improve the TTO instrument.
- Being dependent on others was the worst-case future scenario for RA patients.

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