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ORIGINAL PAPER

Acceptability of less than perfect health states in rheumatoid arthritis: the patients' perspective

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Abstract Some health problems are considered by many individuals as a 'normal' part of ageing. Our aim was to investigate whether patients with rheumatoid arthritis (RA) consider different types and levels of health losses as acceptable beyond a certain age. A multicenter cross-sectional survey was performed involving RA patients at the initiation of the first biological therapy. The EQ-5D and the Health Assessment Questionnaire Disability Index (HAQ-DI) questionnaires were used to describe domain-specific health states. Patients were asked to indicate for each domain from what age and onward (between ages 30 and

80 years in 10 year intervals) they considered moderate and severe problems acceptable or alternatively never acceptable. Seventy-seven RA patients (females 86 %, mean age 50.3, disease duration 9.1 years) completed the questionnaire. Disease activity (DAS28), EQ-5D and HAQ-DI scores were mean 6.00 (SD 0.85), 0.35 (SD 0.36), 1.48 (SD 0.66), respectively. The majority of the patients considered age 70 and beyond as acceptable to have some health problems (EQ-5D: self-care 42 %, pain/discomfort 34 %, mobility 33 %, usual activities 33 %, anxiety/depression 27 %), whilst at ages 30 and 40 as not

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acceptable. Severe health problems were mostly (57–69 %) considered never acceptable, except the ‘Usual activities’ domain (acceptable from age 80 by 50.6 %). The great majority of the patients (77–96 %) were younger than what they indicated as the acceptability age limit. Similar results were found for the HAQ-DI. This small experimental study suggests that RA patients consider some health problems acceptable. This acceptability is age related and varies by health areas. Further larger studies are needed to explore explanatory variables and to compare with other diseases. Owing to the impact acceptability might have on RA patients’ self-evaluation of current health state and decision-making, the topic deserves methodological improvement and further investigation.

Keywords Health status · Rheumatoid arthritis · Acceptability · EQ-5D · HAQ-DI

JEL Classification I19

Introduction

Albeit health, by definition (WHO, 1948) is ‘a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity’ [1], individuals commonly consider the gradual appearance of some health declines as a natural part of healthy ageing. For instance, slowing in mobility in advanced stages of life is usually acceptable for most people or similarly, when the eyes can no longer focus enough to see close objects clearly above a certain age. There is no universal definition of normal healthy ageing [2]. Academic researchers and lay older people certainly have diverse views, and there are cross-cultural differences as well [3]. Traditions, people’s previous experiences and subjective expectations regarding health might also shape what types and levels of disabilities are considered as a normal part of health in the elderly. Moreover, with the development of new medical technologies some health states or symptoms that formerly were considered as ‘normal’ when people age are now viewed as potentially treatable diseases. Loss of teeth, for instance, is no more an unavoidable part of normal ageing with the advances in and availability of professional dental care. Occasional lapses in memory are observed as potential first signs of Alzheimer disease. Joint deformities in the elderly are viewed as probable symptoms of late onset rheumatoid arthritis (RA), an autoimmune disorder with a wide armamentarium of effective therapies. Thus, healthy ageing is a multidimensional, complex and inevitably changing concept and people’s attitudes towards health during the life course are influenced by a broad spectrum of factors. Nevertheless, taking in consideration the impact

people’s beliefs on normal healthy ageing might have on their health behaviour (e.g., evaluating health gains, seeking for medical care, following medical advice) the topic deserves attention [4].

Brouwer et al. [5] investigated the acceptability of health deterioration in a web-based population survey in the Netherlands. They used statements of a generic health status measure, the EQ-5D [6] to assess the acceptability of health decline with age. As compared to previous studies, this research contributed significantly to the literature in providing comparable results with population health state norms. Results revealed that often individuals do indeed consider less than perfect health states acceptable, especially at older ages. Authors highlight that the erosion of health capabilities over time is evident for the society, and this seems to have shifted the society’s reference point for health in advanced stages of life to points below perfect health. Nevertheless, the acceptability is strongly related to the severity of the health state, and the worst states are considered as never acceptable.

In this study we aimed to test these observations from the perspective of patients with a chronic progressive disease, namely RA. This inflammatory condition often starts in middle age and is most common in older people. Hence, perception of health changes as age-related phenomena or rather disease-related symptoms is a relevant issue for RA patients. Furthermore, people with RA, particularly whose disease is not (or cannot be) well controlled, have to face a progressive disability over time and adapt to at least some health problems. Moreover, a shared decision making between the patient and clinician is an explicit requirement in RA care. The ‘treat-to-target’ approach has been introduced in RA care, which aims to attain remission or low disease activity by strict (every 1–3 months) monitoring of patients and therapy adjustments [7]. Setting up the treatment target, however, can be challenging, especially in long-standing cases and patients’ compliance is crucial for the successful implementation. Achievement of the best possible or perfect health state is not necessarily the only and most important goal for RA patients. Poulos et al. [8] proved that RA patients would be willing to accept treatments with lower efficacy or greater risks of side effects if these treatments had lower treatment duration or frequency. Age was shown to interact significantly with patients’ preferences regarding treatment efficacy levels in a discrete-choice experiment by Augustovski et al. [9], involving biological drug-naïve RA patients. Younger patients (≤ 55 years) valued more negatively even small differences in efficacy (e.g., 40 mm versus 30 or 20 mm mean difference on the Patient Global Assessment scale before and after therapy) whilst older patients were more tolerant in this respect [9]. Moreover, it has been demonstrated that higher age is associated with more insufficient knowledge

and lesser information needs in RA [10]. This barrier can also influence RA patients' attitudes towards the acceptance of less than perfect health states.

Hence, there is apparently a need to gain insight into RA patients' preferences in terms of acceptability of health problems. Age related acceptability of less than perfect health states, as Brouwer et al. [5] pointed out, may have implications for the way in which health state valuations should be elicited and how to value health changes at different stages in life. Moreover, a better understanding of patients' perspectives can improve health professionals' approach to giving information, such as to discuss what is achievable, to encourage patients to participate in the therapy and to formulate realistic expectations. These, above all, can help physicians in designing a consensus based therapeutic goal, improving patients' compliance and optimizing the use of costly drugs [11, 12].

The objective of this study was, therefore, to assess whether patients with RA consider certain health problems acceptable and whether this acceptability is age related and differs by health areas. We surveyed RA patients at a significant point of their care, namely at the initiation of first biological treatment. Besides using the EQ-5D descriptive system, we included statements of a disease-specific questionnaire (the Health Assessment Questionnaire Disability Index, HAQ-DI), a simple self-assessment tool for the evaluation of functional abilities in RA [13].

Methods

Study design and patients

The survey was carried out as a part of a multicentre study which aimed to assess characteristics of RA patients starting biological treatment and to explore subjective health expectations and acceptability of health problems. Details of the research and primary results have been published elsewhere [14] and expectations related results are presented in a companion article in this Supplement [15]. In brief, a questionnaire survey was performed in 2009 in 12 hospital based rheumatology centres. Adult patients with RA attending routine care were invited to participate in the study. Criterion for inclusion was also the initiation of first biological drug treatment at the time of the survey. Authorization by the national ethical committee was obtained (ETT-TUKEB 8-66/2009-1018EKU) and patients signed informed consent.

Health state assessment: DAS28, EQ-5D, HAQ-DI

Demographic data, clinical history were recorded and current health state of the patients was evaluated by

validated instruments. Disease activity was assessed by the Disease Activity Score (DAS28) which considers the number of tender and swollen joints of 28 specific sites (evaluated by rheumatologists), one laboratory test on inflammation (Westergren test or C-reactive protein level) and patient's global assessment of disease activity on a Visual Analogue Scale (VAS). The DAS28 can be used to determine whether the disease is under control (high, low activity or remission) and to establish a treatment target score to aim for [16, 17].

The EQ-5D was applied to measure patients' general health state. The questionnaire essentially consists of two pages. The EQ-5D-3L descriptive system comprises five health dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each dimension has three levels of responses: no problems (1), some/moderate problems (2), and unable to do/extreme problems (3). The digits (1, 2 or 3) for five dimensions can be combined in a 5-digit number describing the respondent's health state, which can be converted to a single utility score (EQ-5D score). A validated Hungarian version of the questionnaire is available, however, due to lack of national tariffs the UK utility scores were used in this study. The second part of the EQ-5D questionnaire is a health thermometer (EQ VAS, range 0–100). Higher EQ-5D and EQ VAS scores correspond to a better health state [6, 11].

The validated Hungarian version of the HAQ-DI was used to assess patients' functional state. The HAQ-DI comprises 20 questions in eight categories covering a comprehensive set of functional activities, namely, dressing, rising, eating, walking, hygiene, reach, grip, and usual activities. Each category contains at least two specific component questions. The stem of each item asks over the past week 'Are you able to ...' perform a particular task. The patient's responses are made on a four-level difficulty scale from zero to three: without any difficulty (0), with some difficulty (1), with much difficulty (2), and unable to do (3). The highest component score determines the score of the category and the eight category scores are averaged into an overall HAQ-DI score. Higher HAQ-DI score represents worse functional abilities [13].

Assessment of acceptability of health problems

Statements of the EQ-5D descriptive system and HAQ-DI were used to assess the level of problems RA patients consider acceptable beyond certain ages. Patients were asked to indicate for each EQ-5D-3L statement from which age between 30 and 80 in 10 year intervals they consider the two difficulty levels (e.g., mobility: some problems with walking; confined to bed) as acceptable, or alternatively never acceptable. This method has been successfully used in the Netherlands in a population survey [5]. The

HAQ-DI statements and problem levels ('some difficulty', 'much difficulty' or 'unable to do') were surveyed similarly.

Statistics

Questionnaire data were recorded in IBM SPSS, Release 20.0 (IBM, Armonk, NY, USA) software and descriptive statistics were performed. Furthermore, the average age at which moderate and severe health problems were considered acceptable was calculated for those respondents who did not indicate 'never', and results were set against a non-representative population study from the Netherlands [5]. Findings were also compared to the health state of the general population in Hungary by age-groups [12].

Results

Patients' characteristics

Altogether 92 RA patients completed the research questionnaire and 77 (84 %) of them provided responses on all acceptability-related questions, thus data, of this subgroup were considered for the current analysis. The difference between responders and non-responders was not statistically significant in terms of age, disease duration, DAS28, EQ-5D and HAQ-DI scores. Patients' age was mean 50.3 (SD 12.5) and disease duration was 9.1 (SD 7.7). There were more females ($n = 66$, 86 %) than males in the sample and 65 (84 %) patients were living alone. Disease activity (DAS28), EQ-5D, EQ VAS and HAQ-DI scores were 6.00 (SD 0.85), 0.35 (SD 0.36), 46.2 (SD 21.1) and 1.48 (SD 0.66), respectively. Highest educational level was

primary school, secondary school or university in the case of 21 (27 %), 38 (49 %), 18 (23 %) patients, respectively. Twenty-two patients (29 %) were working full or part-time, 14 (18 %) were retired, 33 (43 %) were disability pensioners, 2 (3 %) patients were students, 3 (4 %) housewives and 1 (1 %) patient was unemployed (response was missing in 2 (3 %) cases).

Acceptability of health problems as indicated on the EQ-5D descriptive system

Results are presented in Table 1. The great majority of RA patients considered severe health problems as never acceptable. The 'Usual activities' domain is an exception as 50.6 % of the patients found acceptable if someone at age 80 or over is unable to carry out housework, family or leisure activities. Ages 30 or 40 years were marked only by very few patients. The majority indicated that having some health problems is acceptable from age 70 (their mean age was 48.6, SD 12.5 years). However, ages 50 and 60 were marked also by many patients as acceptable to have some health problems, especially in the 'Mobility', 'Usual activities' and 'Pain/discomfort' domains. (Table 1) Seemingly a significant rate of RA patients found acceptable to have certain health decline as early as 50 and 60 years of age.

Considering only those patients who did not indicate 'never', the majority of the respondents was younger than the age they pointed as acceptable to have some or severe problems (77–92 and 88–96 %, respectively, across the EQ-5D domains).

Comparison with the results of a Dutch population survey [5] revealed that the highest response rates appeared at the same age categories in both studies with only two

Table 1 Acceptability of less than perfect health states (EQ-5D) beyond a specific age in percentage of respondents ($N = 77$)

Health domains of the EQ-5D descriptive system	Level of problem	Health problems are acceptable from age ... and onward (%)						
		30 years	40 years	50 years	60 years	70 years	80 years	Never
Mobility	Some problems	0	3.9	13.0	26.0	32.5	18.2	6.5
	Confined to bed	0	0	0	1.3	7.8	26.0	64.9
Self-care	Some problems	0	0	3.9	19.5	41.6	28.6	6.5
	Unable	0	0	0	1.3	2.6	39.0	57.1
Usual activities	Some problems	0	0	7.8	31.2	32.5	22.1	6.5
	Unable	0	0	1.3	0	3.9	50.6	44.2
Pain/discomfort	Moderate	1.3	1.3	23.4	27.3	33.8	9.1	3.9
	Extreme	0	0	2.6	2.6	10.4	28.6	55.8
Anxiety/depression	Moderate	1.3	2.6	16.9	11.7	27.3	20.8	19.5
	Extreme	0	0	1.3	5.2	7.8	16.9	68.8

Highest response rate is presented in bold numbers for each item

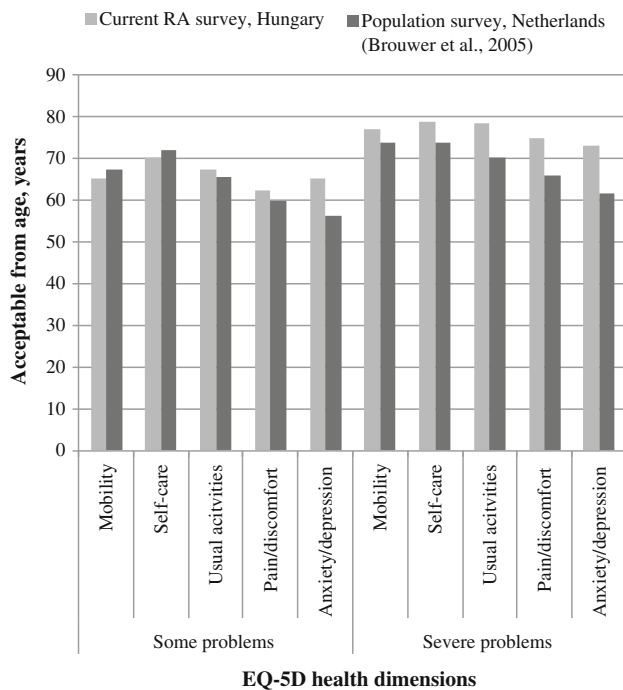


Fig. 1 Average age at which health problems are considered acceptable, as indicated by RA patients who did not indicate 'never': comparison with a population survey from the Netherlands [5]

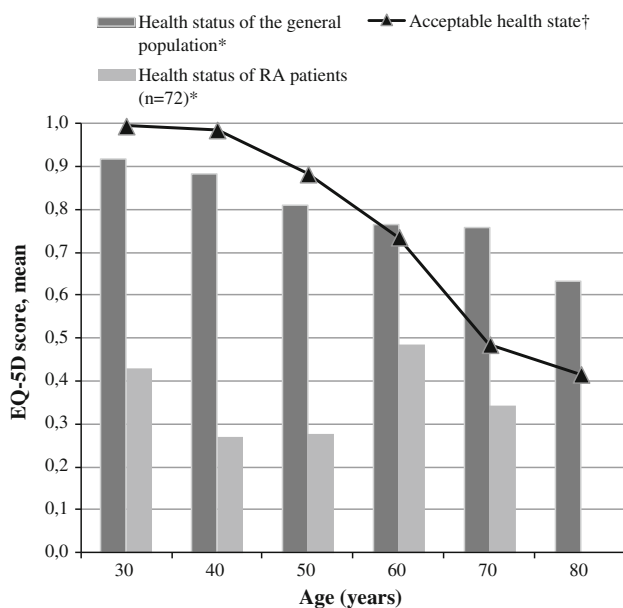


Fig. 2 Health status (EQ-5D) of the general population [12] and RA patients' scores in comparison with the health deterioration that RA patients consider acceptable at certain ages. *Average scores are presented by age groups 25–34, 35–44, 45–54, 55–64, 65–74 and 75–84 years. The number of RA patients in age-groups 18–24 and 75–84 were not sufficient for the analysis. †Deducted score calculated for each age based on the individual responses given to statements of the EQ-5D

exceptions: some problems in self-care were accepted from age 80 and being moderately anxious/depressed as 'never' by the Dutch population sample (the majority of the Hungarian RA patients indicated age 70 for both, see Table 1). However, the distribution of responses was different. For instance, altogether 39 % of the RA patients indicated ages 50 or 60 as acceptable to have some problems in mobility whilst this rate was only 21 % in the Dutch public. Similarly, many more RA patients accepted having moderate pain/discomfort and anxiety/depression from ages 50 or 60 (51 vs. 26 % and 29 vs. 9 %, respectively). Considering only those respondents who did not indicate 'never', we found that severe health problems were considered acceptable from somewhat older ages by the Hungarian RA patients than by Dutch public in all the five domains of the EQ-5D (Fig. 1).

Comparison of acceptable health states to population norms by the EQ-5D

In Fig. 2, we present the average EQ-5D scores of RA patients and the general population in Hungary by age-groups [12]. Health states (expressed in EQ-5D scores) that RA patients considered acceptable for ages 30, 40, 50, 60, 70 and 80, respectively, are provided also on this diagram. RA patients considered better health states acceptable for ages 30, 40 and 50, than the general population actually has in age-groups between 25 and 54 years. The two curves meet at age 60, and an opposite situation is observed for older ages: RA patients accepted worse health states for ages 70 and 80 than the general population's actual scores are at 65–84 years (Fig. 2). It is noteworthy that RA patients' mean health state scores were lower in all age groups than the level they considered in average acceptable for the respective ages.

Acceptability of functional problems as indicated on HAQ-DI

Results are presented in Table 2. Similarly to the findings with EQ-5D, the worst states ('unable to do') were considered as never acceptable by the majority in each of the eight areas of functioning. The level of 'some difficulty' was acceptable from age 70 in general, and 'much difficulty' from age 80. The only exception was the 'some difficulty' in 'Activities' (equally 33.8 % for ages 60 and 70). No difficulties in functioning were acceptable for age 30 and only few patients indicated the age 40, either. The lowest mean age for acceptability appeared in 'Reach' and 'Activities' domains.

In Fig. 3, patients' actual mean HAQ-DI scores are presented by age groups as well as the average HAQ-DI

Table 2 Acceptability of less than perfect functional status (HAQ-DI descriptives) beyond a specific age in percentage of respondents ($N = 77$)

Health domains of the HAQ-DI	Level of problem	Functional problems are acceptable from age ... and onward (%)							Acceptable from age ^a , mean (SD)
		30 years	40 years	50 years	60 years	70 years	80 years	Never	
Dressing and grooming	With some difficulty	0	0	9.1	32.5	37.7	16.9	3.9	66.5 (8.8)
	With much difficulty	0	0	0	5.2	24.7	54.5	15.6	75.8 (6.1)
	Unable to do	0	0	0	1.3	3.9	27.3	67.5	78.0 (5.0)
Arising	With some difficulty	0	1.3	13.0	29.9	32.5	18.2	5.2	65.6 (10.0)
	With much difficulty	0	0	1.3	5.2	27.3	44.2	22.1	74.7 (7.0)
	Unable to do	0	0	0	1.3	3.9	31.2	63.6	78.2 (4.8)
Eating	With some difficulty	0	2.6	2.6	27.3	37.7	23.4	6.5	68.2 (9.4)
	With much difficulty	0	0	1.3	2.6	20.8	50.6	24.7	76.0 (6.5)
	Unable to do	0	0	0	1.3	2.6	29.9	66.2	78.5 (4.6)
Walking	With some difficulty	0	0	9.1	24.7	37.7	22.1	6.5	67.8 (9.2)
	With much difficulty	0	0	0	7.8	19.5	50.6	22.1	75.5 (6.7)
	Unable to do	0	0	0	0	3.9	27.3	68.8	78.8 (3.4)
Hygiene	With some difficulty	0	0	7.8	22.1	48.1	16.9	5.2	67.8 (8.4)
	With much difficulty	0	0	0	6.5	14.3	61.0	18.2	76.7 (6.2)
	Unable to do	0	0	0	0.0	6.5	31.2	62.3	78.3 (3.8)
Reach	With some difficulty	0	2.6	6.5	37.7	39.0	10.4	3.9	65.0 (8.8)
	With much difficulty	0	0	1.3	9.1	31.2	46.8	11.7	74.0 (7.4)
	Unable to do	0	0	0	2.6	7.8	35.1	54.5	77.1 (5.7)
Grip	With some difficulty	0	3.9	5.2	28.6	36.4	20.8	5.2	66.8 (10.1)
	With much difficulty	0	0	2.6	5.2	27.3	46.8	18.2	74.4 (7.6)
	Unable to do	0	0	1.3	1.3	5.2	35.1	57.1	77.3 (6.7)
Activities	With some difficulty	0	2.6	9.1	33.8	33.8	15.6	5.2	65.3 (9.7)
	With much difficulty	0	1.3	1.3	7.8	33.8	41.6	14.3	73.2 (8.3)
	Unable to do	0	0	0	3.9	5.2	39.0	51.9	77.3 (6.1)

Highest response rate is presented in bold numbers for each item

^a Average age at which these problems in functioning are considered acceptable, as indicated by RA patients who did not indicate 'never'

scores that patients found acceptable from ages 30, 40, 50, 60, 70 and 80. A gradual and rather steep worsening of functional capabilities with ageing was accepted in average from 60 years and onward (Fig. 3). Note that acceptable functional states were better than the RA patients' age-matched actual average HAQ-DI scores. This is in line with our findings with EQ-5D as presented above.

Discussion

We have surveyed the acceptability of health problems among RA patients at the initiation of first biological treatment. The most severe health states (e.g., being confined to bed, not being able to perform everyday activities like eating, dressing and grooming or washing themselves)

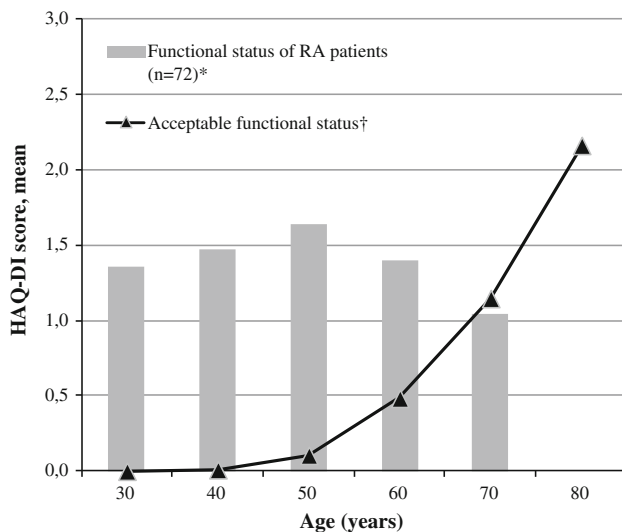


Fig. 3 Functional status of RA patients by HAQ-DI and functional disability they consider to be acceptable at certain ages. *Average scores are presented by age groups 25–34, 35–44, 45–54, 55–64 and 65–74 years. The number of patients in age-groups 18–24 and 75–84 were not sufficient for the analysis. †Deducted score calculated for each age based on the individual responses given to statements of the HAQ-DI

were considered as never acceptable by the great majority of RA patients. Buitinga et al. [18, 19] came to similar conclusions as the scenario of being dependent on others was the most often considered as the worst to experience by RA patients. Our results, nevertheless, indicate that moderate health and functional problems are acceptable from age 70 by the majority, but also a significant rate of patients indicated ages 50 and 60 as acceptability thresholds. In contrast, RA patients seem to consider ages 30 and 40 as too young to have any health problems or functional disability (Tables 1, 2). After that, the curve of acceptability threshold is almost exponential (Figs. 2, 3).

Some variability can be observed across health areas. RA patients seem to be more tolerant to moderate problems presented in the 'Usual activities' than in the other four domains of EQ-5D (Table 1), and similarly, in the 'Activities' among the eight domains of HAQ-DI (Table 2). Overall, rates differ across health domains indicating that acceptability of health problems varies by health dimensions. Sanderson et al. [20] explored RA patients and they confirmed also that patients do prioritize across specific outcomes.

Interesting findings rise if we put the RA acceptability results in the context of the health state of the general population. Comparison by age-groups revealed that RA patients presented higher criteria for acceptable health states than the general public actually has at age of 50 and below (Fig. 2). In contrast, patients accepted much worse states from age 70 and beyond than the general population

in fact has. Our sample was too small to analyse the explanatory variables of this reverse shaped gap. The median age of the sample (52 years) was rather close although still lower than the age (60 years) where the population norm and RA patients' acceptability levels crossed each other (Fig. 2). Hence, we assume that patients' current age might be an important explanatory factor for acceptability estimates. This hypothesis seems to be strengthened by the fact that the majority of the respondents was younger than the age they considered acceptable to have moderate or severe health problems (considering only those respondents who did not indicate 'never'). However, other influencing factors (e.g., sample selection, gender rate, patients' age at the onset of the disease, disease duration or patients' subjective self-expectations regarding future health) might have significant impact as well. Further studies are needed to provide firm evidence.

Comparison with findings of a similar survey among the general population in the Netherlands highlighted many similarities and some differences [5]. Both studies indicated that worse health states are less acceptable than the more moderate ones and the acceptability of health problems is age related. However, a notably higher rate of RA patients than their Dutch counterparts indicated ages 50 or 60 as acceptable for having some problems in walking about, having moderate pain or discomfort and being moderately anxious or depressed. Considering only those respondents who did not indicate 'never', RA patients marked slightly higher ages as acceptable for severe health problems than the Dutch public in all the five domains of EQ-5D (Fig. 1). The discrepancy between acceptability levels and actual population norms (Fig. 2) was detected also in the Dutch study but its pattern was different. There the two curves started from the same point at age 30 and a broadening gap was observed with the increase of age [5]. It is worth pointing out, however, that the mean age of the Dutch sample was 30 years and the acceptability of health problems was not surveyed under this age. Thus, we do not know whether they would present better than realistic states as acceptable for younger people. Nonetheless, comparing Hungarian RA patients with the general population from the Netherlands is obviously only a best available scenario with broad limitations. The life-expectancy at birth in the Netherlands is about seven years higher than in Hungary and this statistically expected longer living might influence people's concerns about acceptability of health problems in older ages. Differences in the economic levels, health, social care and reimbursement systems between countries might also shape how people relate to health, health care and disability problems (e.g., availability and affordability of costly therapies, home care, nursing homes, special aids, etc.) [21–23]. We

cannot exclude the impact of cultural differences, either. Some disparities between the two samples (e.g., age, gender rate, health state) are originated presumably from the nature of the disease. These might also per se have impact on the findings. Therefore, further controlled studies within one country or jurisdiction are squarely needed to draw more forceful conclusions.

Including HAQ-DI, our survey provided additional information regarding the association between age-related acceptability and the severity of health problems. HAQ-DI has 4-level responses whilst EQ-5D has only a 3-level scale. RA patients made a distinction between age 70 and 80 on HAQ-DI as the highest acceptance rates for the level 'some difficulty' appeared for age 70, and for the level 'with much difficulty' for age 80. In contrast, age 80 was indicated only by a minority on EQ-5D, and the highest proportions appeared mainly for age 70 and in the 'never' category (Tables 1, 2). Applying the EQ-5D-5L version with a 5-level response scale could refine our results. Nonetheless, findings with HAQ-DI suggest that patients do indeed care about age when they are thinking about life over age 70. It would be interesting to expand the survey for age 90 and beyond, especially in populations with high life-expectancy.

Direct comparison of Hungarian population norms and patients' acceptability results on HAQ-DI is not suitable due to the disease-specific character of this questionnaire. Nevertheless, some interesting studies deserve mentioning. Krishnan et al. [24] assessed the functional status of a random sample of adults ($n = 1,530$) with a HAQ-DI questionnaire in the Central Finland District. According to their findings, functional disability increased exponentially with age for both genders. For instance, in the case of females, the mean HAQ-DI score was <0.1 under age 50, it increased from 0.16 to 0.77 between age-groups 50–54 and 70–79 of age, and was a mean of 1.49 in the age-group of ≥ 80 . Sokka et al. [25] highlighted that most people over age 50 in the general population do not meet the American College of Rheumatology (ACR) criteria for remission in RA. Having these HAQ-DI 'norms' is a further argument in favour of using HAQ-DI statements in the assessment of acceptability of health problems.

Some limitations of our study must be noted. The sample size was small and not representative, thus, our results cannot be extrapolated to all RA patients who are initiating biological therapy. Other subsamples, such as RA patients in younger age, patients with shorter disease duration or in remission, patients with irreversible joint deformities or requiring institutionalisation might have very different views [26]. We have not explored patients' previous history (e.g., whether they have had experienced the worst health states), this is another important point to consider. We did

not include patients' co-morbidities either (e.g., cardiovascular diseases, fractures or cognitive functions) [27], although these might also influence the acceptance of health problems in RA. Further studies involving larger and representative samples are encouraged to reveal the explanatory factors. Another limitation is the lack of validated instruments to assess acceptability. In this study we used statements of EQ-5D and HAQ-DI and patients evaluated them one by one. It is very likely that patients would have given different results if they had to evaluate combinations of the statements. Nevertheless, this way of surveying (with EQ-5D) was used successfully in a previous research [5], and we have had good experiences as well in terms of feasibility. Alongside the cons, there are pros that justify our approach. The natural course of the disease in RA can be described by HAQ-DI and minimally important difference estimates have been established for both questionnaires [28]. HAQ-DI makes part of a composite index called ACR criteria, which is a core instrument in clinical trials to assess clinical improvement [29]. The HAQ-DI score is often collected in RA registries as well [30]. EQ-5D is the most frequently used tool to measure utility in health economic evaluations in RA [31]. Thus, assessing acceptability of deterioration of general health and functioning in RA with questionnaires based on EQ-5D and HAQ-DI can open the door for comparisons between patients' acceptability concerns and long term cohorts, as well as randomized controlled trial data. Applying the EQ-5D creates the possibility for comparisons across different chronic diseases, another interesting area for investigation. Being aware of the limitations of our study is obviously crucial in the interpretation of the results. Hence, we consider our survey more as a pilot with explorative purposes that confirmed the importance of the topic and revealed promising fields for further research. It is important to mention, and cannot be overemphasized, that our results are not to justify inadequate care or unreasonable patient selection. Contrarily, we believe that the better understanding of age related health concerns can help to bridge the information asymmetry between RA patients and health professionals, and as a result, improve RA patients' health.

In conclusion, acceptability of less than perfect health states exists and is an issue for further discussion in RA. Expanding our knowledge on patients' beliefs regarding age related health might improve the communication between patients and health professionals. Owing to the impact RA patients' reference points for health might have on their needs and compliance, the topic deserves methodological improvement and further investigation.

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