

UNDERSTANDING WHY THE GENERAL POPULATION MAY OR MAY NOT CHANGE THEIR VALUES FOR HYPOTHETICAL HEALTH STATES: A QUALITATIVE STUDY USING RHEUMATOID ARTHRITIS STATES

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INTRODUCTION

The matter of whose quality of life (QOL) values should be considered when appraising health states is a subject of ongoing debate [1]. Gold et al. advocated that these values should be obtained from the general population, rather than from patients [2]. This is based on the premise that valuations from the general population should be used to guide health policy decisions in a publicly funded healthcare system. Conversely, it is been argued that patients, due to their direct experience, are better suited to value their own health [3], although their values may be ‘distorted’ by their ability to adapt to their disease [4]. While it is difficult to take a single viewpoint for using either *only* patients or *only* general population values, the use of *informed* general population values have been proposed to direct healthcare decisions [5-7].

A challenge for researchers is to find ways to inform the general population about the health states they are valuing. Although the health state descriptions can never be thoroughly complete, methods have been suggested to ensure that the respondents do not overlook the effect of illness on common or important life functions. Such methods include offering more descriptive states or providing information on the size and the nature of adaptation experienced by patients; however, there is a trade-off between overburdening the respondents and achieving sufficient realism [7].

Fundamentally, values obtained from the general population are presumed to reveal their preference for living in a particular health state. However, as the respondents may be uninformed about what it is like to live in the investigated health state and unaware that disease adaptation is possible, it has been debated that methods used to appraise health states do not yield well-formed values [8]; these preferences, instead, are more likely to be developed and clarified during the process of participating in valuation surveys. Shiell et al., in particular, stated that if preferences are at first incompletely formed (i.e. individuals are initially uninformed and perceive the health state to be much worse than it actually is) but develop during the process of making the assessment, then the initial values are an underestimation of the true value [9]. This can result in significant implications when the QOL values are incorporated in cost-effectiveness analyses. Alternatively, by allowing individuals the time to reflect upon the different health states, and discuss with others, real life decision-making may be simulated. Results from previous studies

investigating the construction of well-formed values demonstrated that participants, if given the opportunity, do alter their initial QOL values after they are given time to reflect upon, and deliberate on, the health states [10–12].

While the literature shows that QOL values may not be formed when a respondent completes a valuation exercise, there is a paucity of empirical evidence assessing why an individual may opt to alter their health state value when given the opportunity to do so. Thus, the aim of this qualitative study was to gain a greater understanding as to why members of the general population change – or do not change – their health state values after providing both (i) an information session about disease adaptation and (ii) a period of reflection and deliberation. In this work, rheumatoid arthritis (RA) states are used as an illustration. The primary outcome of these results was to develop a questionnaire, which encompassed all possible reasons why individuals may or may not alter their values when appraising RA states; the intention of this questionnaire was to be administered in a large-scale study to be conducted at a later date.

METHODS

To understand why health state values may or may not change, a qualitative methodological approach was undertaken using one-to-one interviews with members of the general population.

Study Participants

Individuals in the City Centre of Sheffield were purposively sampled to ensure a wide range of ages and an equal distribution of sexes. A broad spectrum of ages and sexes was recruited to obtain a sample that would be transferable to the general population. Twelve was chosen as the desired number of individuals to participate in this study; this number was considered sufficient because the main outcome of this study was to develop a questionnaire to address the rationales for changing – and, correspondingly, not changing – QOL values. Of the 12 participants, eight were females, two had arthritis, and a range of different age groups was recruited (Table 1).

Interview Process and Questions

An intervention – known hereafter as the ‘adaptation exercise’ – was used to inform the participants. The material for this was taken from the *Personal Experiences of Health and Illness* website [13]; the site contains recordings of interviews from RA patients of varying age and disease duration. Three interview excerpts, which described different aspects of adaptation, were presented. These excerpts were given fictitious names: ‘Lisa’ described the trials of initially being diagnosed with RA; ‘Ann’ discussed changes she made to accommodate her RA; and ‘Patricia’ reflected on her process of adapting to RA (Appendix 1). Recordings of these excerpts were played during the adaptation exercise and participants were encouraged to reflect upon, debate, and discuss this information.

The design of this study was a modified randomized controlled trial. The participants were randomly sorted into two groups: ‘Initially Uninformed’ and ‘Informed’ (Figure 1). For individuals in the Initially Uninformed Group, the adaptation exercise took place between the first (e.g. ‘cold’) and the second (e.g. ‘warm’) valuations. Participants in either group were asked to complete two time trade-off (TTO) valuation exercises for three states, crudely classified as mild, moderate, and severe RA but labelled as Z, X, and Y, respectively. For individuals in the Informed Group, the adaptation exercise occurred before the first (e.g. ‘warm’) valuation; a second (e.g. ‘final’) valuation was elicited after patient values for three health states of similar RA severity [14] were presented. The main purpose for this design was to alleviate the potential for prevarication bias [15]: evaluating the effect of an intervention with only one group runs the risk of individuals changing their valuations to please the investigator.

At the start of the adaptation exercise, the participants were asked if they knew the common symptoms of arthritis* and whether they knew someone with arthritis. They then listened to the first of the three patient interview excerpts – referred hereafter as ‘recorded scenarios’ – after which a series of questions were asked: (i) can you summarize the information you heard and (ii) have you, or someone close to you, been in a similar situation that the patient described; if not, can you imagine yourself acting in the same manner as the patient? The same questions were repeated after the participant heard the remaining two recorded scenarios. At the final stage, the participant’s TTO values over the course of the session were presented. They were then asked to provide a rationale as to why the first and second TTO valuations differed, if a difference existed; an explanation was also requested if there was no difference between the values. All interviews were conducted by HMC between February and March 2008.

Data Analysis

A member of the research team (HMC) transcribed the interviews. Any identifiable characteristics mentioned during the interview (e.g. names of family members) were removed. The transcripts, once checked, were imported into NVivo (version 7.0), a computer-assisted, qualitative data analysis software package (QSR International, Doncaster, Australia). This programme was used to manage the data and to help facilitate analysis.

* The disease under investigation was generally referred to as ‘arthritis’, rather than as rheumatoid arthritis, to the participants. The intention of this generalized labelling is an attempt to not cognitively overburden the participants with definitions of various forms of arthritis. HMC had clinical definitions of both rheumatoid arthritis and osteoarthritis readily accessible if the participants questioned the distinction between the two terms; however, this was not necessary. As such, the use of the terms ‘arthritis’ and ‘RA’ are used interchangeably throughout this paper to align with the language used with, and by, the participants.

The framework approach was used to analyze the interviews. Framework is often used for applied or policy relevant qualitative research [16]. The use of this approach allowed the exploration of concepts, which are known to be fundamental to QOL values changing (e.g. coping attitudes) and themes, which emerged from the interviews (e.g. empathy). This approach allowed the coding framework to materialize from the data, as well as being informed by existing knowledge of the issue under study. The five stages of framework analysis are discussed below.

Familiarizing

The transcripts were read in their entirety several times. Any recurrent themes that aided in explaining why a participant would opt to change, or not change, their health state values were recorded. In addition, each interview was summarized; this enabled the interviews to be kept in case formats, as well as gain important information without referring to the entire transcript.

Identifying a Thematic Framework

Literature from the fields of health economics and health psychology, which potentially were relevant in understanding why individuals may alter, or not alter, their values for health states, was explored. As some of the participants expressed a greater understanding towards the patients in the adaptation exercise compared to others, the empathy literature was also investigated. The findings from previous studies were discussed between two members of the research team (AOC and HMC). A thematic framework based on the issues emerging from the transcripts and the information found in the literature was developed.

Indexing

All transcripts were coded using the constructed framework. Coding, an umbrella term for the process of organizing qualitative data to assist in retrieval and interpretation, aims to highlight any complexities or contradictions arising from the transcripts. While not all text fragments needed to be coded, different codes, if required, could be applied to the same portion of the transcript. If any part of the transcript did not fit the framework, new codes were developed. These codes were incorporated into the existing framework and used in subsequent coding of the transcripts. When all the transcripts were coded, the framework was re-assessed, such that unassigned codes were eliminated and duplicate codes were combined into a single code. The new framework was then used to re-code the interviews once again to ensure that the new codes, developed from the first coding attempt, applied to all the transcripts.

Charting

After applying the thematic framework to all the transcripts, the next step was to build up the picture of the whole data by considering the range of attitudes and experiences for each issue. The data were 'lifted' from their original context and rearranged according to the appropriate

thematic reference [16]. In an attempt to develop an even greater understanding of the interviews, charts using the headings and subheadings drawn from the framework were created. This not only provided an overview of the data but also enabled comparisons of the perspectives that existed within the participant and observed the range of perspectives amongst participants.

Mapping and Interpreting

Similar codes were clustered together to form sub-themes. The sub-themes were then organized into main themes (e.g. the codes, ‘the need to deny having arthritis’ and ‘do not want to burden others’, belonged in the sub-theme of ‘perception of vulnerability due to a disability’, which were subsequently categorized into the main theme of ‘attitudes toward coping’).

Participants’ quotes were used to illustrate the research findings. These were presented mostly verbatim – including the use of inaccurate verb conjugations and absent pronouns – in an attempt to not alter the participant’s language. The quotations were cleaned by removing interjections (e.g. “ah”, “um”, “like”, and “you know”) and, where necessary, square brackets were inserted to improve the comprehension of what was being communicated during the interviews (e.g. “take their mind off it” became “take their mind off [the arthritis]”).

To develop a greater understanding of the rationales for why an individual opted to change, or to not change, their values for RA states both the participants’ reflections about the recorded scenarios and their direct answers to the questions about changing values were evaluated. Considering only the accounts that the participants provided for why their health state values changed, or did not change, ignored the interpretations of how these individuals felt about people with arthritis and illness, as well as their general life outlook; all of which had a synergistic affect on their willingness to change.

FINDINGS

Five themes that explained why members of the general population may or may not alter their initial health state valuation for various RA states were identified: (i) attitudes toward coping; (ii) views on life with arthritis; (iii) previous illness experiences; (iv) personality; and (v) increased understanding of the valuation task (Figure 2); each is explained below.

Attitudes toward Coping

Perception of Vulnerability due to a Disability

The first of the recorded scenarios in the adaptation exercise is that of Lisa, a recently diagnosed RA patient, who highlights the potential to cover up symptoms from other people. After listening to this scenario, the participants believed that if they had arthritis they might not want to fully disclose everything about their condition to others. In fact, they recognized that this was a form

of dealing with a chronic health condition, albeit a non-laudable option. The participants believed that not vocalizing the “full extent” of the condition to people is a fact of “human nature”, such that other “people don’t want to see you miserable even if you are in pain” (Alice, Informed Group). By “masking” the disability or “vulnerab[ility]”, participants, who indicated that they would cover up their symptoms, chose to do so in an attempt to “be seen as normal – shall we say, in inverted commas – than having some kind of condition” (Simon, Initially Uninformed Group).

The participants felt that, by covering up symptoms, family members and friends would not be burdened; thus preventing them from “treat[ing] you differently”. Without this focused attention, the patient is provided with an opportunity to “forget” about the illness. Those individuals in the Initially Uninformed Group, who viewed that having arthritis is a sign of being vulnerable, increased their QOL value during the second TTO exercise potentially because they had a greater understanding that they can hide the fact that they have arthritis from others.

Interestingly, participants who specified a preference to cover up their symptoms were individuals with no direct experience with arthritis. Patients currently living with arthritis, on the other hand, did not hold this perception; instead, they viewed the need to appear normal as a result of how society perceives individuals with illnesses. Thus, these individuals kept the same QOL value when appraising the RA states for the second time.

[If you have arthritis] you don’t want people to think you’re weak or think anything’s wrong with you so you can appear normal to everybody else ‘cuz you think people might think less of you. I think it’s nonsense [...] [You think] you might not be accepted in society because society doesn’t accept something [...] out of the ordinary, away from the normal. (Clare, Initially Uninformed Group)

Perception of Disease Adaptation

The other recorded scenarios of the adaptation exercise illustrated that, although you are living with RA, a person can continue living a fulfilled life. Upon hearing how Ann kept herself physically fit by setting goals at the swimming pool, a range of positive emotions were expressed by the participants. These ranged from what she has accomplished was “inspirational” and “impressive”, to the fact that “she was going to fight [arthritis] all the way” (David, Informed Group). Some participants began to recognize that a meaningful life and a level of fitness are achievable with arthritis; indeed, a positive change in values was detected for these individuals.

The participants acknowledged that the first step is to “come to terms” with the fact that you have RA. While getting to this stage of acceptance “would take a while”, it depends on the characteristic of the person “because some people do dwell on things and mope around, and some people just get on with it” (Christine, Informed Group). In addition, participants recognized

that a more active process is involved in getting on with life once diagnosed with RA. Referred to as either adapting or coping, it is a stage of “necessity” because participants recognized that changes need to be made in order to “accommodate” living with an illness.

Because if you didn't [adapt to arthritis], you'd drive yourself mad with it, I think. For the sake of your own [...] mental health more than anything [...] you have to find some sort of way around it or you just be miserable constantly, wouldn't you? (Simon, Initially Uninformed Group)

Participants with direct experience with chronic illnesses were more open-minded about altering the activities that they currently enjoyed. They recognized that there is a need to know your “capabilities” and to “prioritiz[e] life slightly differently”; as a result, these individuals increased their TTO values when given the opportunity to do so. Alternatively, those with limited illness experience deemed that making changes would be difficult to perform and be “frustrating”. Individuals who expressed this viewpoint did not choose to alter their health state values when completing the TTO exercise the second time.

I would really struggle imagining making changes to life. I appreciate that I would probably have to but I find [making changes] really difficult to imagine. (Robert, Informed Group)

While many of the study participants indicated a change in their values for the RA states, many of them stated that they would not be willing to exactly match the patient values when these were shown because they did not “understand [arthritis] properly”. However, some participants in the Initially Uninformed Group felt that hearing the recorded scenarios provided evidence that, if patients can cope to life with arthritis, they should be able to cope if they were placed in that situation.

I think it was hearing those three people speak and realizing that it isn't actually the end of the world to be diagnosed [with arthritis]. [...] You can find ways of coping and be positive. [...] I guess I was thinking it was really bad to start with but then heard them: [arthritis] might not be that bad. (Karen, Initially Uninformed Group)

For those in the Informed Group, the presentation of the patient values before their final valuation provided them with proof that an individual can cope with arthritis. Thus, this impacted the individual to change their values for the health states when they completed the second TTO exercise.

When I looked at [the patient values], it made me think that I was really mardy[†] and being pathetic basically [...]. And looking at facts, [...] you do still have a life; so it made me think. [...] I could still have this, I could still

[†] The definition of *mardy* is *to be moody*.

have that. Am I really prepared just 'cuz of my discomfort – extreme pain, or whatever – prepared to give up? (Alice, Informed Group)

Perception of Available Support to Help with Coping

Another factor that affected whether the participants believed that they could cope with living with arthritis was their personal attitudes towards available support, whether provided by family, friends, or their own spirituality. This provided some participants with a sound reason to increase their QOL values because of the belief that they could adapt quicker to the illness due to the support available to them. For example, participants who were close to their families would welcome the help they offered whereas others with a more independent character were too “proud” to acknowledge the need for support and wanted to deal with things on their own. The latter view was mostly adopted by some individuals in an attempt not to “worry others” in what they regarded as their “own battle to fight”.

I believe we come into this life on our own; we leave this life again on our own. We're very alone at those two critical times [...] and you have to learn to deal with that situation yourself [and ...] the support of family, friends, or your loved ones will just need to be given a rest. You can't rely on other people to see you through that pain. [...] That way, if you become too reliant on other people, you could become a burden to family [and] friends. It doesn't help your situation [...] and] you have two lots of people suffering. (Doug, Initially Uninformed Group)

The recorded scenario provided by Ann mentioned that she had a network of friends – both sufferers and non-sufferers of arthritis – at the swimming pool. The participants recognized that having a “wide circle of friends” would allow them to cope better. Specifically, one can “take their mind off [the arthritis]” yet, at the same time, receive support from interacting with other people in the “same position”.

Another aspect that contributed to the participants' attitudes towards available support in their ability to cope with an illness – and, hence, their desire to change their initial QOL values – was their spiritual beliefs. One participant, when she was healing both a concurrent broken back and knee, “held on to the hope” (Sophie, Initially Uninformed Group) until she recovered fully. For another individual, “faith [played] a big part” (Joanne, Informed Group) in how she has coped with arthritis.

Overall, individuals who relied on support – whether from family, friends, or spirituality – increased their health state values after hearing the recorded scenarios. A change was also detected for those who had a more independent character; however, the magnitude of change was not as great as for those who recognized the availability of support to help cope with an illness.

Views on Life with Arthritis

Experience with Arthritis

When the participants described the common symptoms of arthritis, many of the participants expressed pre-conceived ideas of what it would be like to live with this chronic condition. These impressions stemmed directly from interactions with patients with arthritis or indirectly from stereotypes of the disease; the latter may possibly have arisen from media portrayals. The level of arthritis experience affected the impressions individuals had towards the health condition. Of the 12 participants, two individuals had arthritis: Clare had osteoarthritis and Joanne had RA. Half of the participants had varied levels of arthritis experience with family members or friends; this resulted in some individuals being more informed about arthritis than others. Those participants with experience – either with themselves or with someone close – believed that there are “worse conditions to have” than arthritis. However, due to the potential struggles patients may face with their arthritis, *inexperienced* participants envisioned an extreme form of the condition during their initial appraisal of the arthritic health states.

[Arthritis] looks quite stressful and frustrating. [...] Even though you're mentally fit and healthy, your body is just really struggling to keep up [with the arthritis] and move with your mental state, which, I think, is really frustrating for anyone.
(Sophie, Initially Uninformed Group)

As such, these individuals, compared to those with arthritic experience, expressed a lower preference to live in any RA state at first and, after taking part in the adaptation exercise, a change was detected.

An Older Person's Disease

The participants had negative views when considering the age of the patient with arthritis. Upon hearing the first recorded scenario of the adaptation exercise, most participants were in disbelief that Lisa had already been diagnosed with arthritis at the age of 30; in fact, one participant questioned whether the audio clip was indeed “real”. Most thought that arthritis only afflicted older people and considered the patient to be “unlucky” if arthritis developed at an early age.

I don't know how prevalent arthritis is at an early age, but if you're in your thirties, is it some kind of failing that you've got arthritis? And is there the support there for younger people? [...] I don't know. I've only really associated it with the elderly. (Rose, Informed Group)

Since most participants associated older patients with having arthritis (i.e. a characteristic of patients with osteoarthritis), they felt that older people were better suited to cope than the younger because they were in the appropriate “age category”. As such, younger participants did not change their values as much as older individuals.

A Painful Disease

All the participants discussed the concept of pain. Those with minimal or no experience with arthritis – or with any illness for that matter – described the assumed pain as “horrible”, “constant”, and “difficult to accept”. Because of these negative opinions, participants considered arthritis to be a severe health condition that they would not like to have. In addition, a number of participants, when making their assessments, focused on the pain item of the health state description.

I couldn't be able to live with that [...] extreme pain just seems to me that you notice it all the time. (Darryl, Initially Uninformed Group)

After hearing the recorded scenarios, however, the participants gained further insights about what it is like to live with arthritis. At the start of the session, participants thought that the pain experienced when living with arthritis would be quite severe but, after the adaptation exercise, participants began to realize that mild and moderate pain would not be as horrible as they initially thought. Because of this altered perception, individuals valued the states defined as mild and moderate pain higher the second time around; the valuation of the extreme pain state, on the other hand, did not change.

I think listening to the recordings, it made me realize that there was – and actually talking [it] through myself, as well – there was some life with moderate pain. With extreme pain, I would say, there is very little life. (Clare, Initially Uninformed Group)

Previous Illness Experience

The participants' own experiences with chronic illnesses appeared to enable them to understand the message behind the recorded scenarios in the adaptation exercise better than participants without experience with illness; thus an increase in values for the RA for the second time around was observed. One participant, in particular, was able to juxtapose the content in Ann's interview with his own personal health battle.

She was going to fight [arthritis] all the way. It's not let it beat her. [Because of my celiac disease, I was told to] either [...] get rid of your bikes or well, sit in the house and feel sorry for me self, or you're going to try coping and keep going on bike. [...] I try to ride for as long as I can now so [my stomach] don't hurt. So I'm not letting [the celiac disease] beat me. (David, Informed Group)

Similarly, the healthy status of some participants may have prevented them from being fully grasping the message brought forth by the patients in the adaptation exercise, thus reducing their willingness to change their values for the health states.

[When] you're going at the questionnaire, you're looking at from your own perspective, I guess. And from my own specific perspective, I'm in quite good health [...] So if you offer me their scores without the questionnaire – I don't

know. I think I'd still, at this stage, take my own scores because I don't have to cope with the condition. (Simon, Initially Uninformed Group)

An individual's indirect illness experience also played a role in whether or not they changed their QOL values. In particular, seeing how family members dealt with significant life events in a certain way was evident in their responses. For example, one participant described how her father's fight to live longer despite being only given two days of survival made her realize that there is more to life than full health; hence, a positive change in values was observed for this situation. However, the influence of family members' negative experiences had an opposite effect on other individuals; thus, a change in QOL values was not detected. As such, previous illness experience could affect a person's willingness to change in both ways: to change and to not change.

I saw my mother die of a stroke. [...] But she died really because she didn't want to live. She didn't want to live that type of life where she couldn't do anything for herself. Extreme pain has that affect on you; the only way it can affect. [...] You can forget moderate, slight pain but extreme pain, I don't think, you could forget about it. [...] My personal experience is extreme pain makes life not worth living. (Clare, Initially Uninformed Group)

Personality

Attitudes toward a Life Change

The participants portrayed a range of personality outlooks in their responses when taking part in the adaptation exercise. While they did not explicitly state their personality traits in the interviews, these played a role in how they discussed facing a significant change to their lives.

A range of different approaches of how the participants would deal with learning that they had arthritis was observed. Some participants said that they would feel "angry" initially because they would not be able to come to terms with this life-changing event. However, individuals with positive attitudes to life recognized that there would be a need to "investigate" what changes could be made to improve their life. Furthermore, they were more likely to accept the fact that, while they might not be able to do the same things as they did before they developed arthritis, they needed to make the best of the situation that they were given. This optimistic outlook on life was evident in how the participants valued the TTO exercise the second time around: a change in the positive direction was observed.

I can relate to this because, sometimes I think, "I can't achieve this particular thing". [...] I can always surprise myself at the end of day thinking that, "I have achieved and I've done it with ease and I've actually enjoyed the experience". So what it proves you can never dismiss any situation, [no matter] how unlikely it may look at the time. (Doug, Initially Uninformed Group)

Individuals with negative attitudes felt that it would be a “struggle” and a “challenge” to find a substitute for an activity that they currently loved. In cases where moderation would enable an individual to still partake in activities that they enjoyed, one individual, in particular, recognized that this skill, in theory, would work for some people but not for him. As such, no change in QOL value was observed for these individuals.

I think it would be difficult for me personally. [...] I think I would probably over do [things] more [...] I [would] find it difficult, I think, to moderate. (Simon, Initially Uninformed Group)

Empathetic People

Some participants were able to empathize with the patients in the recorded scenarios better than others. This ability to understand the patients’ messages stemmed from both the participants’ past experience of illness and from their personalities. Hearing the recorded scenarios allowed many of the individuals to recognize that people can still have a meaningful life with arthritis; thus a positive change was detected.

[The information presented in the audio-recordings has] broaden my mind. I think ‘cuz [arthritis is] something that didn’t affect me directly. [...] After listening to the [patients ...] my outlook kind of changed. Though [arthritis] is a severe illness, it is not the end of the world. Basically, there are still plenty of opportunities for you still and there’s numerous things you can do. And, yeah, basically, I think I was naïve to it and thought that it was a more horrific than it was. (Sophie, Initially Uninformed Group)

The degree of how well the participants understood the individual recorded scenarios was further observed when the participants consistently used the fictitious names of the patients throughout their responses in their interviews. This provided evidence that these participants were engaged with the entire adaptation exercise and, therefore, that they were able to empathize with the patients. As a result, these individuals who engaged with the adaptation exercise opted to change their values when they completed the second TTO exercise.

Lisa were more in the fed up stage and angry stage, which you’re going to be at that age, I think. [...] I should imagine the longer you have it the more you learn to manage it and know what gives you a bit relief. [...] I thought Lisa was quite sad and then Patricia and Ann were like, “it’s not the end of your life. It’s not the end of your world. [...] You ‘ave to put up with it. You can have a quality of life and things”. [...] So that’s what I sort of got from them. (Alice, Informed Group)

A Desire to Live a Long Life

Some participants recognized that, although you are living with a disability, the number of life years was very important in their assessments. After the interpretation of their personal values for the RA states and the presentation of the patient values, individuals in the Informed Group

opted to change their values when completing the TTO for the second time. Their desire for a greater number of life years, despite the reduced QOL from RA, was a result of wanting to achieve certain milestones in life, such as “want[ing] to see everybody and [seeing my children] grow up” (David, Informed Group). This desire for a long life was a combined effect of the participant’s personality and illness experience, either personally or with family members; affording a change in their values for all the health states. This positive change was a result of individuals realizing that they were giving up so much of something they really wanted and accepting that they could live with a poorer QOL to achieve a longer life.

[Arthritis] is obviously manageable, if you like; you can put up with it. [...] [Giving up] 18 years [of my life to not have arthritis]: I must ‘ave had a mental block. (Alice, Informed Group)

Understanding the Valuation Task

The final attribute that contributed to an observed change in the health state values was the individual’s understanding of the valuation task. Valuing the three states using the TTO approach resulted in some difficulties for many of the participants because, for most of them, it was their first time participating in a health valuation study. Because of the novelty of the TTO exercise, one individual indicated that changes observed from the values of the three arthritic states were not a result of hearing the recorded scenarios or seeing the patient scores but rather a greater understanding of the valuation exercise the second time around.

My outlook was the same for the first task and the outlook was same for the second task as the first task [...] My outlook is the same since I walked through the door. I would only give up, or be prepared to give up, so many years if my health could be so bad. So what it is my interpretation of the question is different for the second time. (Doug, Initially Uninformed Group)

DISCUSSION

The qualitative interviews demonstrated that an individual’s decision to change their initial health state values is based on: (i) coping attitudes; (ii) views on life with arthritis; (iii) previous illness experiences; (iv) personality; and (v) increased understanding of the valuation task. These themes, although described as distinct entities, are, in fact, highly interrelated. For example, the ability of individuals to empathize and engage with the patients in the adaptation exercise is affected by their past experiences with illness, which is affected by their personalities.

As the content in the adaptation exercise encouraged the participants to think about coping strategies and living with arthritis, it was not unexpected that these aspects affected an individual’s willingness to change their QOL values. Interestingly, change was also influenced by an individual’s personal experiences and characteristics. We assumed that individuals with either direct or indirect experience of long-term illnesses, or with personalities that enabled them

to adapt to life changes and empathize with others, would have made their initial appraisal of the health states based on these underlying factors. However, this was not observed to be the case. These individuals had to be reminded of these issues through the use of the recorded scenarios as prompts in the adaptation exercise; the health state descriptions on their own were not enough to evoke this knowledge.

Consistent with findings from previous research, the results from the current study demonstrate that QOL values are indeed not well-formed initially and, through the use of an information session and reflection and deliberation periods, an individual's values can be altered. Specifically, the use of the adaptation exercise informed participants about what it is like to live in the investigated health state and, thus, was effective in altering their initial QOL values. There has been minimal effort in previous research in producing more realistic health state descriptions in valuation studies: a small handful of studies have attempted to inform the respondents about what it is like to live in the health states [e.g. 17–20]. Of these studies, only Happich et al. evaluated the impact of informing the general population respondents [20]; however, the education session had no effect on their valuations.

This study was not the first to conduct an adaptation exercise; at least two published studies incorporated adaptation exercises to aid the general population in their valuation of hypothetical health states. This, however, was the first to utilize interviews from patients to promote concepts of disease adaptation. Damschroder et al. used an intervention that encouraged healthy respondents to consider their own ability to adapt emotionally to negative events in general and specifically in relation to being paraplegic [21]. The findings from that study indicated that, after randomly allocating the respondents to the adaptation exercise, the values assigned to the paraplegic states increased after the intervention. In another study, a task was implemented that prompted individuals to think about a previous emotionally challenging life event and how their emotions relating to that event changed over time [22]. In general, the exercise encouraged the respondents to think that the QOL of a chronically disabled individual would improve over time.

While the intent of the adaptation exercise for this current study was primarily to educate the participants about the eventual possibility of adapting to a specific health condition, it also served to personalize the health states. By creating fictitious names for each of the recorded scenarios, some individuals empathized with the information contained in the adaptation exercise better than other individuals. Empathy is broadly defined as the ability of an individual to react to the experiences of another individual [23]. More specifically, empathy is also referred to as “the capacity for knowledge of the emotional state of another person, regardless of one's own

emotional state” [24]. From the interviews, the individuals’ degree of empathy arose from their personality traits and their experiences with illness.

The results from this current study also support the claim that providing a reflection and discussion period can impact an initial value for health states. Providing the opportunity to think and talk about the information presented in the adaptation exercise coincides with the way some individuals formulate decisions in reality. This has been evaluated empirically by a few studies but the results have been inconclusive [10–12]. Dolan et al. found that, at first, respondents from the general population wanted to give lower healthcare priority to smokers, heavy drinkers, and illegal drug users [10]; however, after group discussions, their opinions changed, such that they were indiscriminative towards them. The results of the remaining two studies found that a reflection and deliberation process influenced the individual’s answers, although there was no significant impact at the aggregate level [11,12]. Specifically, Stein et al. found that the respondents considered the discussion period to be important because it provided reassurance about their initial values; confirmed their assumptions regarding the health states; increased group cohesion; and satisfied their curiosity about the health states [12].

Limitations

Although the design of this study was novel in the use of interviews of patients in encouraging concepts of disease adaptation, the order in which the interviews was played may have affected the participant’s decision to alter their initial QOL value. By starting with a negative recorded scenario (i.e. Lisa’s interview) and then improving the messages in the subsequent recorded scenarios (i.e. Ann and Patricia’s interviews), this may have potentially led the participants to subconsciously increase their values. However, this did not affect all participants, as they did not consistently change their values for the second TTO exercise.

While the results from this study add to the current literature about the construction of values, the use of interviews placed some limitations on this study. Responses represented the views and opinions of the participants at the time of the interview and cannot be viewed as either definitively true or false [25]. Furthermore, the sampling method may have affected the results. By recruiting participants in the City Centre of Sheffield, the research may not be transferable to the general population in terms of health status. For example, individuals of ill health would be less likely to walk along the High Street compared to more healthy individuals. By including only those individuals who agreed to participate, the results may be subject to volunteer bias.

In addition, the still-developing skills of the interviewer (HMC) were revealed in occasionally awkwardly phrased questions, unnecessarily rigid adherence to the interview topic guide, and missed opportunities to follow up on interesting points. As the study progressed, these areas were

improved and quality data was obtained. Furthermore, the desire of the lead researcher for people to change their values so that positive results were obtained may have impacted on how the questions in the interviews were asked, especially for the first few interviews. However, as the interviews were transcribed while recruitment for participants was still ongoing, the delivery of the interview questions was modified during the data collection process to ensure neutrality.

CONCLUSIONS

Through the use of qualitative methodology, the individuals' willingness to alter their previous QOL values was determined to be influenced by five attributes: (i) their attitudes toward coping; (ii) their views about life with arthritis; (iii) their previous illness experiences; (iv) their personality; and (v) their increased understanding of the valuation task. While this preliminary study was small in size, these results will feed into a future large-scale study by developing a questionnaire, which assesses an individual's rationale to change – and, equally as important, to not change – values for RA states when given the opportunity to do so. By administering this questionnaire to a large number of respondents recruited from the general population, and randomly allocating them to either the Initially Uninformed or Informed Groups, we will be able to gain a better understanding of the formation of informed general population values.

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TABLES

Table 1: Characteristics of the Study Participant

Study Participant *	Age Group	Group	Has Arthritis?	Experience with illness?
Clare	>50	Initially Uninformed	Yes	Yes
Darryl	20-29	Initially Uninformed	No	No
Doug	>50	Initially Uninformed	No	Yes
Karen	20-29	Initially Uninformed	No	No
Simon	30-39	Initially Uninformed	No	No
Sophie	20-29	Initially Uninformed	No	Yes
Alice	40-49	Informed	No	Yes
Christine	20-29	Informed	No	No
David	40-49	Informed	No	Yes
Joanne	>50	Informed	Yes	Yes
Robert	<20	Informed	No	No
Rose	30-39	Informed	No	No

*Not participant's real name.

FIGURES

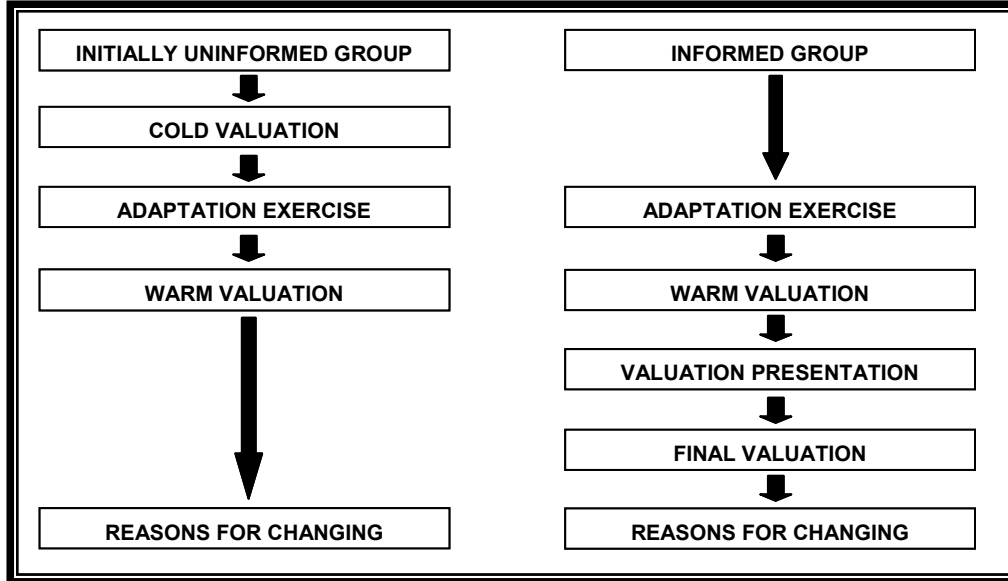


Figure 1: Data collection overview

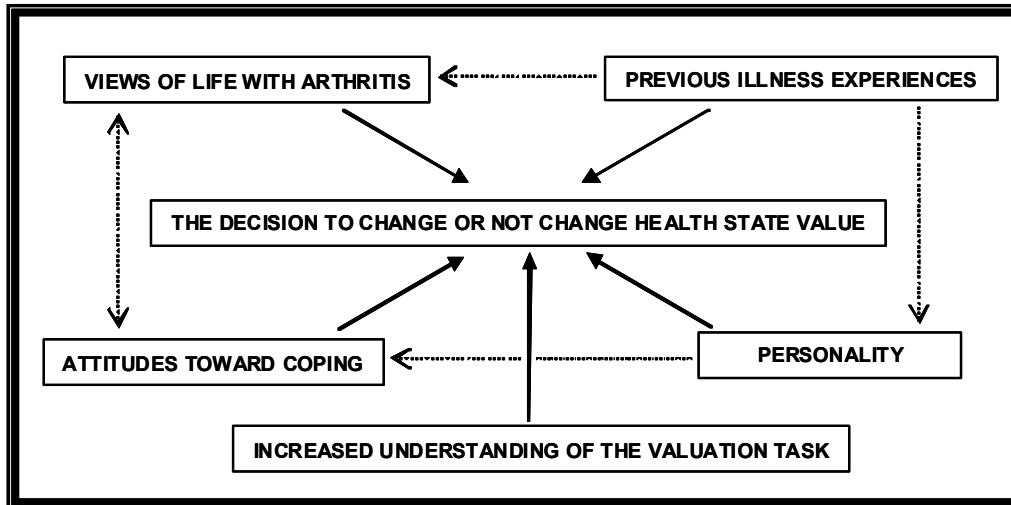


Figure 2: Themes that affect an individual’s decision to change or not change their health state value

APPENDIX 1: RECORDED SCENARIOS USED IN THE ADAPTATION EXERCISE

Lisa’s interview

I didn't let anyone know how bad it was. You put a front on. It wasn't until I got indoors that I'd do the little weeping and the wailing kind of thing [laughs]. So yeah, I don't, I don't think they really knew, like, as I say, my Mom didn't know until we'd gone to [the] Zoo, how bad I was. And she was really, really shocked. 'Cuz I just didn't tell, you know, I'd just got on with it. Struggled, I didn't, you know, I didn't cope with it, I struggled. But as far as everyone else was aware it wasn't as bad as, you know, obviously for [daughter's name] and my husband, they didn't really know how bad it was. So I did cope with, I could go to Hollywood, couldn't I? I could be in Hollywood. But no, I did, I did really, yeah, yeah, I did cover it.

I think one instance we'd gone to, we'd gone out with my brother-in-law and all our families and I was, just sat down normally. I was sat in a club kind of thing, you know, sat down having a drink and it was just like, 'I've got to go to the toilet' and it took me about five minutes, to get up, to get up and get out of the chair. And you know people were going, “We didn't realize you were that bad”. 'Cuz I just couldn't get my body to do anything.

Ann’s interview

But, and then I think it was about two years ago now I started swimming and that has just been fantastic. Because that is something I can do and I do it five days a week, every morning. I started off it, doing, it was this time of year, October, I got into the pool and I could do 35 lengths and I thought by Christmas I want to swim a mile and at Christmas I did. I was doing my 64 lengths in the hour.

And now there's a new pool opened, and the same group of people go, and we all sort of, I mean they're not all sufferers, some just go because they enjoy going but we all sort of support each other, if you like, and I haven't been for two days this week so I'm already in trouble.

But I can swim now for about an, well I could swim for two hours if I wanted to but I don't because I have other things to do, but I, I have found that that has helped and my consultant, you know, just sees me, says, 'ah my swimmer'. You know, he's, he's really impressed that of the you know, the way I've sort of dealt with it. I didn't think, "Ah, my life has ended, I'm never going to be able to do anything". I just thought "Well okay, this is what it is and I'm not going to let it beat me, you know". So I don't, I try to do everything as I did before, but in moderation and that seems to have worked quite well so far. I do still have bad days and sometimes the medicine upsets me.

But I would say in general I feel better now than I did, you know, sort of four or five years ago.

Patricia's interview

As I said earlier on, there are three ways you can deal with arthritis and I've found this out personally when I first started this. You can be very angry and fight it. That only lasts for a certain time because the only one that's getting hurt is you. 'Cuz the more of a temper and, and that you get in the more you create, "Ooh that hurts", sort of thing.

The other thing is you can give in right from the beginning and you can say, "I can't do that". And let everybody else do it for you and give no thought to the fact that they've got their lives to live and they shouldn't be feeling that way that they've got to do it for you. And the third thing is to come terms with it and don't live against it, live with it. And when you get a bad pain just sit, whatever suits you. If you get a bad pain and painting the wall gives you relief, go and paint the wall. If you find, like me myself, the only way to get over it is to just sit quietly and rest and it will go.