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HEDS Discussion Paper 09/02

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No. 09/02

A Qualitative Study Exploring the General Population's Perception of Rheumatoid Arthritis after being Informed about Disease Adaptation

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Abstract

Purpose: This study aimed to gain an understanding of what factors induce individuals to alter their opinions about a health condition after being informed about disease adaptation and being given time to reflect and deliberate on this information. Rheumatoid arthritis (RA) states are used as an illustration.

Methods: Semi-structured interviews were conducted with 12 members of the general population. They completed two time trade-off exercises for three RA states and underwent an adaptation exercise (AE) which consisted of listening to recordings of patients discussing how they adapted to RA. Also included was a structured discussion to encourage the participant to reflect on how the patients have adapted. Participants were shown their own health state values, as well as patient values.

Findings: After being informed about disease adaptation and reflecting on the information, participants were more likely to consider adaptation and alter their opinions of RA if they were able to empathize with the patients in the AE. This enabled individuals to feel that they could cope by reflecting on their experience of RA in family and friends, by drawing on others for support if they had RA, and by having a positive attitude towards life.

Conclusions: The results demonstrate that there is a range of reasons for which people change their perceptions about RA; this requires further exploration.

Key words: health state valuation, qualitative research, quality of life, disease adaptation

1. Introduction

Optimal allocation of resources is a crucial issue in publicly funded healthcare systems. One way to ensure that resources are being spent to the best advantage is the use of cost-effectiveness analysis (National Institute for Health and Clinical Excellence, 2003). This analysis increasingly measures the benefits of medical interventions using the quality adjusted life year (QALY) rather than units specific to the condition under investigation. The QALY provides a generic unit of measurement for comparing across different programmes of healthcare. By combining the time spent and the value individuals place on living in a specific health state, the QALY incorporates information on both the quantity and quality of life (QOL) in a single index.

The current recommendation is to obtain these health state values from members of the general population, who are asked to envision life in the disease state, rather than from patients who are actually in that state (Gold et al., 1996). The premise behind this is that the general population's perception of different health states is unbiased, and hence will lead to policy decisions that best represent societal priorities. The drawback, however, of using general population values is that they may not understand the implications of living in the investigated health state. They may only consider the affected life domains and, more importantly, may not consider the possibility of adapting to the disease (Menzel et al., 2002). As these could impact the outcomes of cost-effectiveness analyses, Gold et al. (1996) advocated that values should be obtained from 'informed' members of the general population. However, current practice is to obtain values from the general population with little or no preparation and, arguably, they are not well 'informed' about the states of health.

The challenge is how best to inform respondents about the health states they are valuing. As the general population tend to underpredict their ability to adapt to an impaired state (Kahneman and Snell, 2000), one method is to provide information on the size and the nature of adaptation experienced by patients alongside the health state description (Brazier et al., 2005). By including evidence about adaptation, and a period to consider

and discuss this information, respondents – if they choose to do so – can incorporate it into their appraisals.

Currently, there is an absence of empirical evidence exploring the construction of general population values collected from participants who have been informed about patients' abilities to adapt to their diseases. Specifically, this study aims to gain an understanding of what factors influence members of the general population to alter their perceptions of the condition under investigation after being informed about disease adaptation and being given time to reflect and deliberate on this information. Rheumatoid arthritis (RA) states are used as an illustration.

2. Methods

Individual face-to-face interviews with members of the general population were undertaken to understand patterns in responses to an adaptation exercise (AE). These responses, in turn, were used to generate hypotheses to determine the factors that influence individuals to alter their valuations for health states after informing them about disease adaptation; these hypotheses will be tested in a future study.

2.1 Participants

Individuals in a city in the north of England were purposively sampled to obtain a range of ages and sexes. This ensured a sample that would be transferable to the general population. Twelve people were interviewed (Table 1): seven were females, two had arthritis, and a range of ages was recruited. Responses from 12 participants were sufficient to identify an array of reasons individuals might have for changing their opinions of RA after being informed about disease adaptation.

2.2 Interview Process

The interview process incorporated various exercises and discussion. Material for the AE was taken from the *Personal Experiences of Health and Illness* website (DIPEX, 2007). Three interview excerpts, which described different aspects of adaptation, were played: '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).

Participants were randomly sorted into two groups (Figure 1). Each group completed two identical time trade-off (TTO) exercises consisting of three RA states of different severities (McTaggart-Cowan et al., 2008) and underwent the AE. For the TTO, participants chose between two alternatives, both with certain prospects: 25 years in the hypothesized state or x years – where x varied from zero to 25 years – in full health; both prospects were followed by death. Individuals in Group 1 completed the first valuation before undergoing the AE; the second valuation concluded the session. For those in Group 2, the AE occurred before the first valuation; the second valuation was elicited after patient values for similar health states (Tijhuis et al., 2000) were presented. As such, deliberating on the AE was expected to make the first and second valuations for Group 1 differ; for Group 2, the first valuation was expected to be influenced by the AE and any observed changes in the second valuation would be due to reflection on the patient values.

At the start of the AE, all participants were asked if they knew about arthritis¹ and whether they knew someone with arthritis. They then listened to the first of the patient interview excerpts – referred to hereafter as the 'recorded scenarios'. They were encouraged to reflect on the content of this recorded scenario through a series of questions: (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? The same questions were repeated for the two remaining recorded scenarios. At the close of the session, the participant's values over the course of the session, along with the patient values, were presented to both

¹ During discussion with the participants, the disease under investigation was generally referred to as 'arthritis', rather than as rheumatoid arthritis. This attempted to avoid cognitively overburdening the participants with the definitions of the various forms of arthritis. The interviewer had clinical definitions of both rheumatoid arthritis and osteoarthritis readily accessible if the participants questioned the distinction between the two terms; however, these were not used in any of the interviews. As such, the terms 'arthritis' and 'RA' are used interchangeably throughout this paper to align with the language used with, and by, the participants.

groups. They were asked to speculate as to why their first and second valuations – and why their values and the patient's – differed if discrepancies existed; an explanation was also requested if there were no observed differences. The participants were interviewed in person on the university campus by the lead author and received £10 to defray time and travel costs. The University of Sheffield ethics committee approved the study protocol.

2.3 Data Analysis

The interviews were tape-recorded and transcribed verbatim. The transcripts were imported into NVivo (version 7.0), a computer-assisted, qualitative data analysis software package (QSR International, Doncaster, Australia), to manage the data and to facilitate analysis.

The interviews were analyzed using a framework approach, as it is a common method for applied or policy-relevant qualitative research (Ritchie and Spencer, 1994). It allows the exploration of concepts which are relevant to the research question and themes which emerge from the interviews. This approach allows the coding framework to materialize from the data, as well as being informed by existing knowledge of the issue under study. A thematic framework was constructed and all transcripts were coded using the framework. Data were rearranged according to the appropriate thematic reference using charts with headings and subheadings drawn from the framework (Ritchie and Spencer, 1994). This enabled comparisons of the perspectives that existed within the participant between the first and second TTO exercises and the range of perspectives amongst participants. Links were drawn between themes derived from the interviews and the understanding gained from the literature. The findings were illustrated by the participants' quotes.

To understand what aspects of the AE influenced the individual's perception of RA, both their reflections about the recorded scenarios and their answers to the questions about changes in their valuations were evaluated. It was important to consider both, as focusing on the accounts that the participants provided as to why their values changed ignored the

interpretations of how they felt about people with arthritis and illness, as well as their general outlook on life.

3. Findings

Six themes that explain what influences members of the general population to alter their opinions about RA were identified (Figure 2). The description of the themes was then used to generate hypotheses to determine why individuals may change their values for RA states.

3.1 Coping Attitudes

Upon reflecting on the information presented in the AE, people began to realize that they could cope to life with arthritis. Specifically, they started to understand that patients can cope with their condition by covering up their vulnerability related to having RA; by making lifestyle changes to accommodate RA; and by drawing on support from others to ease difficulty associated with RA. As such, we expected that individuals who considered these coping techniques would be more likely to change their health state values than those individuals who did not think about them.

Ability to Hide Vulnerability. Some participants felt that if they had arthritis they might not want to disclose everything about their condition to others. In fact, they recognized that this was a form of dealing with RA. By “masking” the disability, 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” (Participant-5). Those individuals who initially viewed having arthritis as a sign of being vulnerable improved their opinions about arthritis due to a greater understanding that they could hide their symptoms from others.

Making Lifestyle Changes. The AE encouraged the participants to feel that they could live a fulfilling life even with RA. They recognized that an active process is involved with “coming to terms” with RA. Participants recognized that changes would have to be made in order to “accommodate” the implications of their illness on their lifestyle.

However, the responses indicated that some participants were more open to the possibility of making changes than others. For those who were willing to consider lifestyle changes, their opinions of arthritis improved because they recognized that there is a need to “prioritiz[e] life slightly differently” (Participant-12) if you have a chronic disease. Other individuals deemed that making lifestyle changes would be “frustrating”:

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. (Participant-11)

In addition to the recorded scenarios, the presentation of patient values provided participants in Group 2 with further evidence that coping with a debilitating disease is possible.

When I looked at [the patient values], it made me think that I was really mardy² [...]. And looking at facts, [...] you do still have a life; so it made me think. [...] I could still have this, I could still have that. Am I really prepared just ‘cuz of my discomfort – extreme pain, or whatever – prepared to give up? (Participant-7)

Available Support. Another factor that affected whether the participants believed that they could cope was their attitude towards support. After hearing the recorded scenarios, participants who reported being close to their families developed a more favourable impression of arthritis because they felt they would get the support to help them cope. Alternatively, others with a more independent character were less inclined to alter their perception of RA because they preferred to cope with illnesses on their own.

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. (Participant-3)

Related to this was another type of support: the individuals’ spiritual beliefs. One individual “held on to the hope” (Participant-6) when dealing with her own back and knee problems; while “faith [played] a big part” (Participant-10) for another individual in helping her cope with RA. In these cases, their perceptions of arthritis improved because the AE encouraged these individuals to think about these support mechanisms.

² The definition of *mardy* is *to be moody*.

3.2 Views of Life with Arthritis

Upon reflecting on the content of the AE, participants explored their initial views of arthritis. Specifically, participants discussed their experience with arthritis. Thus, we hypothesized that those individuals with arthritis experience were less likely to alter their values than those who did not have this experience.

Experience with Arthritis. Half of the participants either had arthritis themselves or knew somebody who did and therefore believed that there are “worse conditions to have”. Inexperienced participants, on the other hand, envisioned an extreme form of the condition when appraising the states initially. After hearing the recorded scenarios, inexperienced participants were more willing to change their opinions of RA; although many stated that, after viewing their personal and patient values at the end of the session, they would not alter their values to exactly match those of the patients because they felt they still did not “understand [arthritis] properly” (Participant-6).

An Older Person’s Disease. Most participants thought that the condition only afflicted older people and considered the patient to be “unlucky” if arthritis developed at a young 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? [...] I don’t know. I’ve only really associated it with the elderly. (Participant-12)

When completing the first valuation, most participants in Group 1 believed that older individuals were more likely to develop arthritis. Thus, they felt that the elderly were in the appropriate “age category” to cope with RA. However, after being informed that arthritis could occur at any age through the AE, their impressions of living with RA improved because they were able to picture themselves better in the health states and envision the coping process.

3.3 Previous Life Events

Reflecting on the information in the AE enabled the participants to refer back to their previous life events; in particular, their experiences with illnesses and pain. As such, we speculated that those individuals with significant illness or pain experiences were less likely to change their values when compared to individuals without these previous experiences.

Experience with Illness. The participants' own experiences with chronic illnesses enabled them to understand the AE better than those participants without this experience. One participant 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 letting 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 [my health problem] beat me. (Participant-9)

Similarly, the healthy status of some of the participants may have prevented them from fully grasping the messages in the AE.

[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. (Participant-5)

The AE prompted participants to recall previous illness events. This affected an individual's understanding of coping differently. For example, Participant-7 described how the recorded scenarios made her think about her father's fight to have a longer life despite having a lowered QOL. However, the influence of negative illness experiences had an opposite effect on other individuals:

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. (Participant-1)

As a result, the recall of past experiences affected the individual's perceptions of coping differently.

Not as Painful as First Perceived. Those with minimal or no experience with pain described it to be "difficult to accept". Because of these negative opinions, these participants initially considered RA to be a severe condition that they would not like to have.

I couldn't be able to live with that [...] extreme pain just seems to me that you notice it all the time. (Participant-2)

After reflecting on the AE, participants began to realize that the pain would not be as "horrible" as they initially thought and that they could still partake in many of the activities that they enjoyed.

3.4 Personalities

The AE encouraged the participants to discuss their outlook on life. From the discussions, it was generally apparent whether the respondent had either positive or negative outlooks on life or had an empathetic nature. Although they were not asked to explicitly describe themselves in this fashion, it was evident in their conversation about health and life. As such, we hypothesized that those individuals with positive attitudes and empathetic natures were more likely to change their values than those with negative and non-empathetic personalities.

Attitudes toward a Life Change. Participants expressed a range of different approaches for how they would initially deal with arthritis. Some said that they would feel "angry" because they would not be able to come to terms with this life-changing event. However, individuals with positive attitudes were more likely to accept 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 in.

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. (Participant-3)

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.

Empathetic People. Some participants were able to empathize with the patients in the AE better than others. The recorded scenarios helped these individuals to put themselves into the position of the patients.

A real sign of the participant empathizing with the patients was how some participants consistently used the names of the patients throughout their responses. This provided evidence that these participants were engaged with the entire AE and that they were able to empathize with the patients’ messages.

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. (Participant-7)

3.5 Desire to Live a Long Life

Reflecting upon the AE made the participant realize that, while life with a disability may be undesirable, giving up a significant number of life years to avoid it was a detrimental cost. Specifically, reflecting on their personal and patient health state values made the opinions of RA of some individuals in Group 2 change because they desired a greater number of life years “to see everybody and [my children] grow up” (Participant-9). Individuals realized 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. As a result, we expected these individuals to improve their health state valuations because they desired a longer life.

3.6 Increased Understanding of the Valuation Task

The participant's understanding of the valuation task improved during the session. Because of the novelty of the exercise, one individual indicated that changes observed from the values of the three RA states were not a result of hearing the recorded scenarios 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, is my interpretation of the [TTO] is different for the second time. (Participant-3)

However, none of the other respondents indicated that this was a factor, and hence it is not expected to have had a significant impact on changing the health state values.

4. Discussion

The interviews demonstrated that, after administering an AE, an individual's perception of arthritis can alter due to: coping attitudes; views on life with arthritis; previous experiences; personality; desire to live a long life; and increased understanding of the valuation task. Although this study was not the first to use an AE to aid the general population in the valuation of hypothetical health states (Ubel et al. 2005; Damschroder et al., 2005 and 2008), it was the first to empirically evaluate the reasons for individuals to alter their opinions of arthritis after being informed about disease adaptation and being given a time for reflection. These opinions, in turn, were used to generate hypotheses to determine what makes 'informed' individuals change their health state values. Previously, there has been minimal research informing the general population respondents about what it is like to live in the health states (e.g. Clarke et al 1999; Lee et al. 2000; Cappelli et al. 2001; Happich and von Legerke, 2005). Only one study evaluated the impact of informing the respondents and their education session had no effect on the valuations (Happich and von Legerke, 2005).

The current AE encouraged the participants to think about coping strategies and living with arthritis; thus, it was not unexpected that these aspects impacted an individual's perception of RA. Interestingly, however, individuals had to be reminded of their past

experiences, personality, and desire to live a long life by listening to the recorded scenarios and reflecting upon disease adaptation and patient values; the health states on their own were not enough to evoke this knowledge. Although the aforementioned themes affected an individual's willingness to alter their impressions of the health states when they underwent the second valuation, it is unclear to what extent they affected an individual's initial valuation; this is the subject of an ongoing investigation.

4.1 Study Limitations

Although the design was novel in the use of recorded scenarios by real patients to display concepts of disease adaptation, the order in which they were presented may have affected the participant's perception. By starting with a negative scenario and then improving the messages in the subsequent scenarios, this may have potentially led the participants to subconsciously improve their opinions of RA. This, however, did not affect all participants, as positive final impressions of RA were not consistently observed.

While these results add to the literature about the construction of informed values, the use of interviews represent the views of the participants at the time of the interview and cannot be viewed as either definitively true or false (Denzin and Lincoln, 2000). Furthermore, by recruiting participants in the city centre, 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 in town than healthy individuals. By including only those individuals who agreed to participate, the results may be subject to volunteer bias.

Although it may seem like a limitation that only 12 interviews were conducted, a broad range of themes were extracted and there was evidence that topic saturation was achieved; after nine interviews, no new themes emerged. Of the 12 interviewees, two were individuals with arthritis; the interviewer was not aware of this information until the session was underway. While an individual's experience of arthritis was expected to influence their perception of the health condition, it was ethically difficult to obtain such information when approaching prospective participants. However, as the aim of this study

was to explore what influences the general population's opinions of arthritis, the inclusion of two arthritic patients in the sample is important as the general population is composed of healthy individuals and those with chronic illnesses.

5. Conclusions

This study demonstrated that the use of the AE encouraged individuals to consider the possibility to adapt to a disease. As a result, individuals altered their perceptions of life with RA. The key aspects that led individuals to adjust their valuations were an increased empathy for the patients in the AE and a realization, that by making changes to lifestyle, it is possible to adapt to what at first appears to be a debilitating condition.

The identified themes will be used in a future study to determine the reasons why individuals make the decision to change their values for RA states after being given the AE. This will give us the opportunity to link the rationales identified here with the magnitude of change. By eliciting this information from a large and representative sample, a better understanding of the construction of general population values informed about disease adaptation can be achieved.

6. Acknowledgements

Helen McTaggart-Cowan is supported by a doctoral research award from the Canadian Institutes for Health Research. The project is funded by the Arthritis Research Campaign and Astra Zeneca. The authors thank the study participants for their time and effort and DIPEX for allowing use of the patient interviews available on their website. The usual disclaimer applies.

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Table 1: Characteristics of the study participants

Participant ID	Sex	Age Group	Has Arthritis?	Illness Experience?
<i>Group I</i>				
Participant-1	F	>50	Yes	Yes
Participant-2	F	20-29	No	No
Participant-3	M	>50	No	Yes
Participant-4	F	20-29	No	No
Participant-5	M	30-39	No	No
Participant-6	F	20-29	No	Yes
<i>Group II</i>				
Participant-7	F	40-49	No	Yes
Participant-8	M	20-29	No	No
Participant-9	M	40-49	No	Yes
Participant-10	F	>50	Yes	Yes
Participant-11	M	<20	No	No
Participant-12	F	30-39	No	No

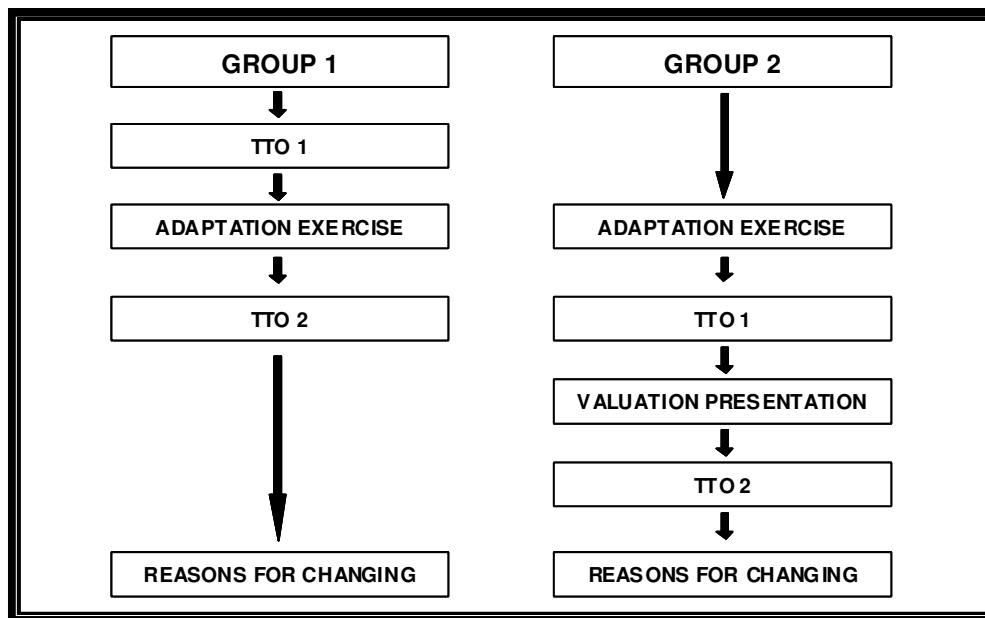


Figure 1: Data collection overview

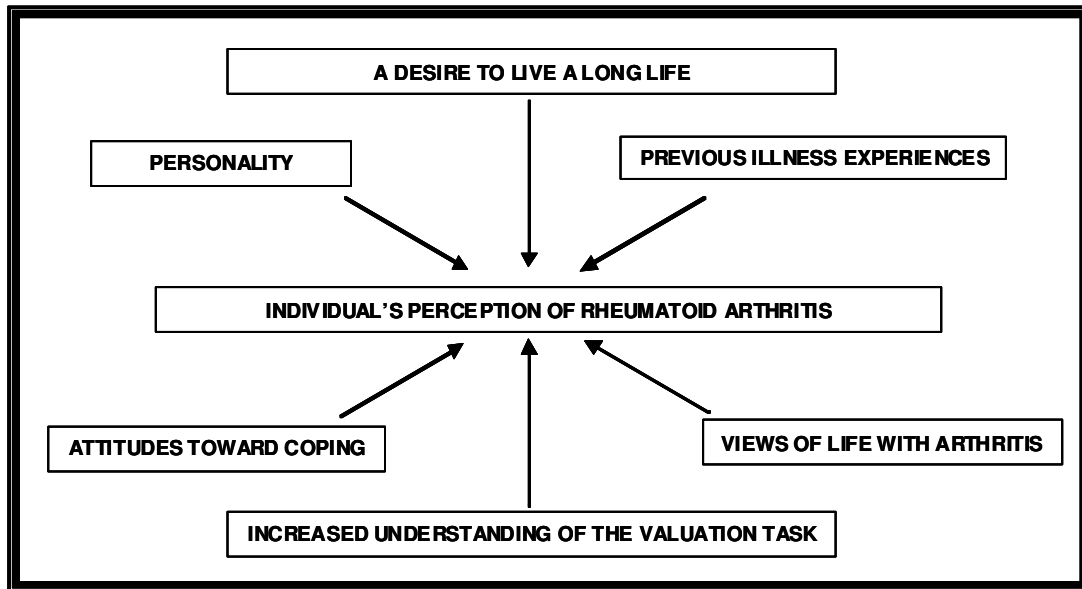


Figure 2: Themes that affect an individual's perception of rheumatoid arthritis after being informed about disease adaptation

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.