

# **“It’s this whole picture, this well-being.” Patients’ understanding of ‘feeling well’ with rheumatoid arthritis.**

## **Objectives**

The aim of this study was to explore the meaning of ‘feeling well’ for people with rheumatoid arthritis (RA).

## **Methods**

In-depth interviews were conducted with 23 RA patients, purposively sampled for medication type, disease duration, disease activity, age, and gender. Data were analysed using Framework, emphasising participants’ personal context.

## **Results**

Well-being was viewed as a broad concept, with ‘feeling well’ being the result of an on-going process to actively engage with a changing body, self and life. Four dimensions emerged: ‘Living in the body’, ‘Being in the mind’, ‘Adapting to illness’, and ‘Being in the world’. The physical impact of RA underpinned the global perception of well-being and was clearly described as linking to the experience of psychological well-being. Physical and psychological wellness was often affected by individual’s adaptation to RA and personal context (e.g. home environment, broader social attitudes).

## **Discussion**

Well-being is a multi-dimensional concept that is meaningful to RA patients regardless of medication type and disease severity. Patients commonly illustrated a process of actively engaging in cognitive and behavioural adjustments to move towards wellness. Clinical practice and research must take account of the complexity of well-being in long term conditions, in order to fulfil patients’ expectations.

## **Keywords**

Adaptation, Patient perspective, Qualitative, Rheumatoid arthritis, Well-being,

## **Introduction**

Rheumatoid arthritis (RA) is a chronic inflammatory autoimmune disease, causing swollen, painful joints, and characterised by fluctuating inflammatory activity.<sup>1</sup> The long term prognosis is highly varied among individuals, and although an overall trend of progressive disability was previously reported,<sup>2</sup> recent studies of aggressive early treatment with combination medications show that disability may be prevented and even remission induced.<sup>3</sup> This chronic condition has a global impact on individuals' lives, and may affect not only physical functioning but also self-esteem, role, relationships, control perceptions and mood.<sup>4</sup> People with RA have repeatedly described 'feeling well' as an important outcome of treatment,<sup>5</sup> and have experienced this on recently developed medications (anti-TNF therapies).<sup>6</sup> However, patients' understanding of well-being in the context of living with RA has not been established.

## **Well-being in health policy**

In policy documents, there is common rhetoric around the importance of patients' well-being, but without definition of what this means. Recent National Health Service (NHS) policy documents emphasise a duty of care for the health *and* well-being of its patients.<sup>7,8</sup> The only NHS report to define well-being states that it is 'the subjective state of being healthy, happy, contented, comfortable and satisfied with one's quality of life'.<sup>9</sup>(p.99) There is recognition that treating the health problem in isolation, particularly in long term conditions (LTC), is unlikely to be sufficient, and that working with social services and other organisations will provide more sustainable improvements.<sup>9</sup>

Consideration of the broader biopsychosocial impact of illness is also evident in RA-specific guidelines. For example, the National Institute for Clinical Excellence (NICE) recommends that access to a multidisciplinary team should provide the 'opportunity for assessments of the effect of RA on patients' lives (such as pain, fatigue, everyday activities, mobility, ability to work or take part in social or leisure activities, quality of life, mood, impact on sexual relationships)'.<sup>10</sup>(p.76) However, there is little evidence that the psychosocial aspects of disability are formally assessed in clinical practice or that health professionals are equipped to address these. For example, although psychological support for people with RA is a current NICE recommendation,<sup>10</sup> there appears to be no standardised screening for psychological distress<sup>11</sup> and a lack of knowledge and confidence

amongst nurses about dealing with it.<sup>12</sup> Therefore, health professionals' ability to promote well-being may not match policy rhetoric that it should be provided.

### **Perspectives on well-being**

Outcome-orientated approaches to well-being have dominated the medical literature. Negative affect has frequently been measured as an indicator of the impact of ill health on psychological well-being (e.g. RA depression review<sup>13</sup>), commonly using the Hospital Anxiety and Depression scale.<sup>14</sup> The broader impact has been assessed using quality of life (QoL) instruments, which measure the patient's evaluation of life across different domains. However, the definition and measurement of QoL is not standardised,<sup>15</sup> and it is not clear whether QoL is conceptually synonymous with well-being. Disease-specific QoL tools have been developed for use in clinical trials (e.g. the RAQoL scale<sup>16</sup>), but are unlikely to effectively capture the processes behind patients' changing priorities and adjustment to a LTC that may impact on QoL outcomes.

In other disciplines, process-orientated approaches to well-being may be more successful in capturing this dynamic experience of (un)wellness from the patient perspective.

Psychological approaches have focused on the cognitive appraisal of and affective (emotional) responses to illness. For example, the Self-Regulation model was developed to describe how people make sense of ill health through illness representations: a process of identifying the illness, looking for its cause and cure/control, likely consequences and duration.<sup>17</sup> The ability to cope with the outcome of this process (e.g. realising that RA is currently incurable) is likely to affect patients' experience of wellness. Another important concept is 'response shift', which is a psychological reaction to change, and refers to 'changes in the meaning of one's self-evaluation of a target construct'.<sup>18</sup>(p.1508) It consists of three interrelated constructs: 'recalibration', a change in internal standards in response to a health state change; 'reprioritisation', a change in values or priorities; and 'reconceptualisation', a change in definition of health. It is feasible that the same changes in meaning occur to standards, values and definitions of wellness or well-being. Ryff and Keyes argued that well-being research in psychology has been data driven rather than based on a clear conceptual framework.<sup>19</sup> They developed a multi-dimensional model of psychological well-being (PWB) for the general population, with six components of positive psychological functioning: autonomy, personal growth, self-acceptance, life purpose, mastery, and positive relatedness.<sup>19</sup> A eudaimonic approach, focused on human

potential or flourishing rather than happiness, to well-being in long term conditions, may be more productive than only assessing affect intensity and regulation.<sup>20</sup>

Sociological research in chronic illness has provided extensive evidence of the personal experience of illness beyond the symptoms, including the ‘biographical disruption’ caused by the illness,<sup>21</sup> ‘narrative reconstruction’ to make sense of the condition,<sup>22</sup> and the ‘shifting perspectives’ of wellness and illness depending on the context.<sup>23</sup> The theorisation of individuals’ experience of chronic ill-health has shifted over time: from a focus on loss and burden, towards images of health within illness, transformation, and redefining health.<sup>24</sup> That is, to a recognition that wellness may be experienced despite living with a LTC. Wellness has become more prominent in the sociological literature, with studies of lay perceptions of illness also eliciting the importance of re-establishing a new sense of well-being. For example, in interviews with people with traumatic brain injury, adjustment to their new life and to loss of ‘complete health’ was essential to feeling well.<sup>25</sup> In another interview study, which focused on self-management in chronic pain and RA, patients described that a sense of well-being was achievable through various mind/body techniques.<sup>26</sup>

Assessment and valuations of health outcomes have been shown to differ between patients and health professionals,<sup>27</sup> and definition of concepts such as well-being, health and disability may also differ. Current standard measurements of disease activity and impact decided upon by health professionals and researchers may not measure outcomes important to patients, such as well-being. RA patients’ understanding of health and QoL have been explored in a Swedish interview study.<sup>28</sup> Health was primarily associated with being healthy/being free from disease, able to function normally, having a healthy lifestyle, and experiencing well-being. However, that experience of well-being was not described or defined. QoL overlapped partially with health (being healthy and functioning normally), but also included having a positive outlook on life, having a good social network and living conditions. It is unclear whether patients’ perceive ‘feeling well’ as a multidimensional concept that overlaps with health and QoL, or whether it refers to improvement of an RA-specific systemic unwellness caused by inflammation or a flare of disease activity. With advancements in medications, which may improve patients’ outcomes or even induce remission of disease, it is essential that improvement as well as deterioration is measurable.<sup>29</sup> Therefore, it is important to determine what ‘feeling well’ means to RA

patients, so that it can be accurately assessed. This study was part of a larger project to elicit treatment outcomes important to patients and develop a patient set of priority outcomes.<sup>30,31</sup> The aim of this paper is to explore how people with RA understand the concept of well-being.

## **Methods**

Individual interviews were conducted since they are well suited to researching complex phenomena such as well-being and allow an in-depth understanding of the participants' personal context.<sup>32</sup> Recruitment of interviewees commenced with patients who had received anti-TNF therapy (a type of drug that blocks the proteins that cause inflammation), since descriptions of well-being were most evident in this group in the literature. Subsequently, patients who had not received anti-TNF therapy were invited to be interviewed. Patients were purposively sampled for disease duration, disease activity, age, work status and gender. A brief questionnaire was administered immediately prior to the interview to collect further participant characteristics, including demographics and the Disease Activity Score patient global scale (to indicate disease severity),<sup>33</sup> the Health Assessment Questionnaire (HAQ: functional disability),<sup>34</sup> a well-being scale ("In general, what percentage of well-being do you feel?").<sup>35</sup> These data were used in subsequent recruitment discussions with potential participants to ensure that people with a range of disease impact experience and perceptions of well-being were recruited.

An interdisciplinary literature review on RA treatment outcomes, well-being and normality was conducted and informed the topic guide (Table 1). Interviews began with a general invitation to "Tell me about your health" and more specific themes identified from the literature were followed up. This approach enabled data to emerge spontaneously before prompting was required to ensure that key areas were covered. Interviews were conducted by T.S. and lasted between 75 to 105 minutes. A Grounded Theory approach was used for the research, in order to explore the construction of meaning of well-being in relation to people's experience of RA.<sup>36</sup> An iterative approach was taken, analysing interview data during the data collection period to ensure that interesting leads could be followed in subsequent interviews. The interviews were recorded and transcribed verbatim. Ethics approval was granted by Bath Local Research Ethics Committee (ref. 07/Q2001/30). Participants were informed of the confidentiality of their data, and that they were free to

withdraw from the study at any time and this would not affect their medical care. Written consent was obtained from participants prior to interviews.

Initially, coding was used according to Strauss and Corbin's guidelines<sup>36</sup> and managed using NVivo2 software. However, after coding five transcripts it was decided that using NVivo2 fragmented the data and made it difficult to consider the informants' contexts. Therefore, an analytical tool called Framework<sup>23</sup> was employed for managing the data. The process of analysis has similarities, although the terminology differs. Data were analysed by first indexing (coding) data on well-being; second, grouping similar indexes to form themes (categories); and third, entering indexed data into the Framework (in an Excel spreadsheet) with themes (in columns) and participants' stories (in rows) providing context. This was an iterative process, with the possibility for new themes to be added from later transcripts. Constant comparison was employed to look for similarities and differences between indexes and then themes. Using Framework to organise the data enabled the dynamic process of how people construct well-being in the context of RA to emerge, and, in practice, was compatible with the Grounded Theory approach. Two participants' transcripts with differing experiences were analysed by four of the team members and differences in indexing discussed. The remainder of the data were analysed by the first author. Labelling of themes using participants' words, and attribution of subthemes such as social support, were decided in collaboration with two patient research partners. The main patient research partner (P.R.) was on the steering committee and was also involved in the topic guide design and dissemination.

## **RESULTS**

Interviews with 23 patients were conducted, including 13 patients on anti-TNF therapy (4 on etanercept, 5 on infliximab and 4 on adalimumab), and 10 on other types of medication (including 4 who had discontinued anti-TNF therapy) (Table 2). There was a wide variation in disease duration, disease activity, functional disability and perceptions of well-being, which indicates that participants with a broad range of experience were recruited. First, the breadth of meaning of 'feeling well' is described. Second, the process of the patients' journey towards experiencing well-being is illustrated.

### **The meaning of feeling well in RA**

The complexity of factors that RA patients were considering in relation to ‘feeling well’ was immediately apparent. Four major themes contributing to feeling well were generated by patients: ‘Living in the body’, ‘Being in the mind’, ‘Adapting to illness’, and ‘Being in the world’ (Figure 1).

### **Living in the body**

This theme was formed from the embodied, on-going experiences of living in the body with RA, consisting of four subthemes(in bold): ‘RA under control’, ‘Focus not on body’, ‘Doing things’, and ‘Having a healthy body’. Perceptions of well-being were affected by the degree to which the **‘RA was under control’** through medication or other treatment. The interviewees’ accounts of (un)wellness incorporated the need for long term management of fluctuating symptoms of the disease. Pain reduction was the most commonly described sign of ‘RA under control’ and made living in a chronically ill body more comfortable:

“Once I’d got rid of the pain I wouldn’t feel so grouchy and I’d be able to do things more.” (AP)

Both pain and fatigue have physical and psychological components, and the above quotation illustrates their interconnectedness in patients’ descriptions. “Fluey” feelings and fatigue associated with flares of inflammation were described as systemic experience of unwellness:

“Some people describe it as a fluey feeling ... you can’t be bothered with things and you just really want to sleep.” (AN)

**‘Focus not on body’**, where attention was no longer overwhelmingly focused on symptoms, was commonly a direct consequence of ‘RA under control’. Being able to forget the RA was a key component of wellness:

“If there are times when I can forget about arthritis, focus on other things, then life must be going reasonably well.” (AY)

For those with severe disease, forgetting the condition was only possible through self-management strategies such as distraction from pain. The exception was those patients who had dramatically improved on anti-TNF therapy and reported no symptoms:

“There are some weeks where I’ve actually forgotten to inject on the day allocated. If I’m feeling well enough to forget the medication then things are going pretty well.” (AK)

**‘Doing things’** was also closely related to ‘RA under control’ because symptoms could be a barrier to ‘normal’ activities of daily living (ADL) and valued activities that provided satisfaction and achievement:

“I’ve been feeling really good the past week because I did food shopping, cooked dinner every night.” (AH)

“I get cross when I can’t do the things I want to do or I had to postpone them or I had to put them off or I didn’t feel very well in doing them, so I took that much longer.” (AB)

There was a clear link between participation in activities and emotional well-being in general. In addition to pain, stiffness and disability from joint damage, the ability to function and participate could be inhibited by RA-related fatigue:

“Well-being is being able to do things and it’s not a struggle, you’re happy. You can get the satisfaction of doing things and being happy tired, not achy painy tired.” (AA)

**‘Having a healthy body’** describes optimal well-being. There were two contrasting approaches to this. First, there were descriptions of a healthy body being unobtainable, and an implication that a complete feeling of wellness was not achievable. Second, some interviewees perceived their body as healthy despite the RA. This second approach was the result of either 1) people with RA were positioning the condition in relation to their otherwise healthy body, or 2) perceiving others’ as having worse health:

“I’m lucky; I’ve got good lungs, a good heart, blood pressure’s fine, no false teeth. I feel healthy despite the RA.” (AX)

“Once you’ve got over the shock, you realise there’s a lot of people who are worse off, you know, with terminal cancer.” (AG)

It is important to remember that many of these patients have severe disease and irreparable joint damage, and any reconceptualisation of health or well-being must be seen within this context.

### **Being in the mind**

The psychological impact of RA was described by every interviewee. The label ‘Being in the mind’ was chosen in collaboration with the patient partners to convey the interviewees’ heightened awareness of their psychology, due to the effects of RA and consequently on changes in well-being. The subthemes were: ‘Positive feelings’, ‘Having a healthy mind’, ‘Holistic identity’ and ‘Support of close others’ (Figure 1). **‘Positive**



**feelings'** were an integral part of feeling well and were affected by lack of treatment efficacy, disease severity, and presence of stress. Therefore, where treatment controlled the disease, an improvement in symptoms enhanced people's emotional wellness:

"On anti-TNF, there's not so many down moods as before because you had pain. It's changed how I feel because you don't get so low. [...] I'm not so wary of falling down, getting stuck, not being able to go further, or my joints locking" (AC)

"[On Enbrel] you just feel more positive about yourself and about life. I don't feel such a burden on other people. You can cope by yourself better. So, yes, it makes me feel more positive" (AQ)

However, there were contrasting descriptions of how much emotional well-being was influenced by disease activity and joint damage:

"When you've got the pain you feel miserable. It's just like something's taken over you and that you're losing control of what you want to do." (AR)

"There are times when I might be very unwell as far as the arthritis goes, but it doesn't particularly affect my overall sense of well-being and happiness." (AN)

Stress caused by the condition and treatment (e.g. surgery) or life events (e.g. bereavement, redundancy) could disrupt psychological wellness:

"I had 5 ops involving legs in plaster for 3 months in last 6 or 7 years. My husband couldn't deal with it and we've since divorced. He couldn't cope with the fact that I was in and out of hospital all the time. In every way it spoils, it affects your life. I shouldn't say 'spoils', but it certainly has a devastating effect on things." (AY)

"They were offering voluntary redundancy and I took that in the end, which was a bit of a worry at the time because I was the main wage earner. To think I can't do this job anymore, I just can't for the sake of my health, it's a bit scary." (AG)

A common component of '**Having a healthy mind**' was an interest in life and participating in activities. Making new attempts (e.g. at activities, finding work) was a sign of increasing mental well-being. Confidence, self-worth and mental clarity were described as other features of a healthy mind that could be affected by flares of RA:

"I enjoy doing craft and jigsaws. [...] When I have a flare, I think "I can't". I would lose interest." (AP)

"If you don't have any pains then your whole outlook is completely different, your confidence is much better." (AO)

There were two sources of support for psychological well-being. First, when health professionals treated 'people' rather than 'patients' or 'conditions', a person's '**Holistic identity**' was maintained:

“Doctors see their own problems, their own field of interest. You have to have a holistic approach, I’m a whole body. [...] There’s so many variables in your life, what you do for a living, your interests and occupations.” (AX)

“I began to think that I became less of a person and more of a condition. I still feel that he [rheumatology consultant] would see one part of me and the consultant at the chest clinic would see another part of me and somewhere in the middle they’d be actually asking the real me.” (AQ)

Second, the knowledge that the **‘Support of close others’** (family or friends) was available when requested:

“My husband’s been helpful. He took over some jobs he knows I can’t do. I can’t do polishing or housework, with my hands I just can’t do it, it’s ridiculous. [...] My son bought us a bungalow in [place] last Xmas. He said he was only doing it to make it easier, that when I’m ill he could run me round, he’d do things for us ...” (AR)

“My father has been incredibly helpful and supportive. Whenever he saw anything in The Telegraph [about RA], or whatever it might have been, he would always cut articles out.” (AK)

Therefore, psychological well-being was a combination of positive psychological functioning and access to appropriate professional and social support.

### **Adapting to illness (managing)**

This theme was important in explaining the observed inconsistency between the severity of RA symptoms or impairment, and overall perceptions of feeling well in the quantitative data (Table 2). There were cognitive and behavioural aspects of adaptation (Figure 1). **‘Feeling OK despite RA’** illustrated the process of reconceptualising health and well-being to enable feeling normal or well despite symptoms or irreversible joint damage. Interviewees described how this acceptance and adaptation could be a long process:

“I think it takes a long time to know when you’ve accepted it, [...] rather than always try to be 100% fine and always reach for what’s very impossible.” (AM)

The majority of interviewees realised the importance of attitude in managing RA. For some this was perceived as an inborn determination or innate positive attitude, but for others it was something that needed cultivation:

“The doctor we had [...] he said to my mother that I would probably end up in a wheelchair by the time I was 45. That sort of gave me a determination...” (AF)

“A lot has to do with yourself and how you approach life and I just am very fortunate that I was born quite a happy person.” (AT)

**‘Getting on with it’** emerged from practical self-management strategies (e.g. self-prescribing analgesics, finding new ways of doing things, pacing) and efforts to fight the disease or prognosis:

“If I want to cut the carrot I put the wider end on the chopping board, place the knife at the top, and sort of just guide it down. Otherwise I can’t cut a carrot.” (AP)

“I’m basically saying “You’re [the disease] not going to take me over”. It’s fighting it.” (AU)

Personal control through self-management, as opposed to ‘RA under control’ through medication, was valued as contributing to feeling well by those with longer disease duration. Conscious trade-offs between being active and the consequent inflammation, from exertion, were made:

“Sometimes I overdo it, and you’ve got yourself to blame, but on the other hand if I hadn’t done it, I wouldn’t have had a good time.” (AG)

Both accepting the condition (e.g. AM above) and fighting it (AU) could be positive strategies depending on the context.

### **Being in the world (contextual)**

There were two contextual influences on perceptions of feeling well. First, **‘Positive circumstances’** provided security in the face of an unpredictable chronic illness, and could impact greatly on the sense of well-being. Personal circumstances included material well-being (e.g. financial security), and the physical home environment (e.g. adaptation for mobility restrictions):

“I’m quite lucky that I live in a nice, quiet area, not a place with lots of stairs.” (AQ)

“Where I’ve moved to you’ve got a bath and you’ve got an en-suite with a shower [Before] I just had to have an all over wash.” (AH)

Interviewees wanted health professionals to be aware of stressors, since they impacted on their ability to manage their RA. Another external stress that could lead to a deterioration of well-being was the health care system that patients were navigating in order to manage their condition. However, this was only mentioned by the male participants in this sample:

“I should be having regular blood tests, once a month and that. But I don’t bother now ... because there’s a lack of joined up thinking, I don’t get the results.” (AA)

Stresses, such as delays in test results, may compromise self-management and risk negating coping skills.

**‘Social attitudes’** affected the formation of perceptions of feeling well with RA.

Negative attitudes could impact on the interviewees’ ability to reconceptualise their life with a chronic condition or on their sense of self-identity:

“People see you every day, you know. There’s a man who looks quite well, you know, never goes to work. That was a big, big um downer to struggle with that, to face people, guilt trips.” (AA)

“You can imagine as a 14-year old saying to your friends: “Oh I’ve got arthritis”. Everyone thinks it’s an old person’s disease.” (AY)

Feeling normal and maintaining or returning to a normal life were important aspects of feeling well, which reflect normative processes:

“And the arthritis goes up and down, and when I’m well I can live a relatively normal life. When I’m very unwell that’s a different story.” (AH)

“Having a disability of any sort is, puts you apart from kind of normal people, doesn’t it? I think I’ve been quite an independent person and I don’t like to feel I need help from people but what else can you do when you’re in pain or not being able to do something. The end is that you’ve got to stop and you’ve got to let somebody help you and that’s quite a difficult thing.” (AQ)

The complexity of normality in the context of RA will be reported elsewhere.

### **The journey to feeling well**

Patients described feeling well despite RA because this captured multiple dimensions of their lives and was not solely focused on physical health or the experience of living in the body:

“It’s this whole picture, this well-being. It’s like a frame into which you fit a lot of other various things about your life.” (AB)

“Health is just a medical term, how everything is working properly. Well-being is about how happy you are with everything.” (AM)

In her analysis of transcripts, the patient research partner (P.R.) focused on the patient’s journey towards well-being. For example, for participant AG she mapped the journey from fear, through frustration, coping and acceptance, to regaining a sense of confidence and wellness. Using Framework as an analytical tool, people’s journeys of moving from

a state of unwellness at diagnosis towards the possibility of wellness over time were evident. Table 3 provides an example of this process through a vignette.

Generally, although physical symptoms were felt to be well assessed and were targeted for treatment, interviewees wanted health professionals to acknowledge their broader well-being over the longer term:

“It’s important to get the whole well-being of that person: what they’re doing, how they’re feeling about themselves, coping with the disease.” (AM)

“It would be useful to talk about how you’re coping emotionally with it all. It’s very easy to put on a brave face for a short time.” (AN)

Interviewees did not expect clinical staff to directly address employment, housing and family problems, but wanted them to recognise the person beyond “the patient, full stop” (AL) and be able to signpost where they might access help for issues having an effect on their arthritis and global well-being.

## **Discussion**

In our study, well-being in RA was shown to be a multi-dimensional concept formed of four themes: ‘Living in the body’, ‘Being in the mind’, ‘Adapting to illness’, and ‘Being in the world’. This conceptualisation of well-being emerged from participants with large variations in disease severity, functional disability and perceptions of well-being. Physical health, characterised by a lessening of symptoms, participation in activities, and non-awareness of the body, was an important contributor to feeling well, but was not necessarily a prerequisite for global perceptions of well-being with RA. Some interviewees with active disease and high functional disability also reported feeling well. In these cases, psychological well-being, adaptation and contextual factors became important sources of wellness. This study indicates the possibility for feelings of well-being in RA, and potentially for other chronic conditions characterized by chronic pain, fatigue or disability.

## **Implications for theory**

The physical impact of RA on perceptions of wellness is unsurprising and links to recent research on patients’ definition of flare, which includes both specific symptoms, such as pain and fatigue, and systemic indicators, such as “fluey” feelings.<sup>37</sup> Living in a body with RA included a conceptualisation of ‘having a healthy body’, which was both seen as

unrealistic when joint damage had occurred and yet feasible when someone had incorporated their RA into a new definition of health. This indicates the importance of determining how an individual relates to their disease, body and self, and the response shift that may have occurred, resulting in a reconceptualisation of values or definitions of health. Therefore, it may be an oversimplification to state that patients' understanding of health is an absence of symptoms or impairment, or being disease free and being able to function normally.<sup>28</sup> Changing conceptualisations of health, well-being or normality may result from individuals' adjustment to illness, in addition to increasing tolerance of pain, fatigue and disability. Therefore, response shift is an essential aspect of understanding patients' ability to develop a sense of wellness in spite of severe disease activity and impairment.

### **Implications for well-being assessment**

The study has important implications for the measurement of well-being in RA. Beaton et al. described how RA patients reviewed not only the resolution of disease symptoms, but also the readjustment of life and redefinition of self and health when assessing outcomes from treatments,<sup>38</sup> and therefore response shift should be considered in measurement of well-being, to reflect patients' experiences. In edentulous and stroke patients, response shift has been shown to mask treatment efficacy over 3 to 6 months,<sup>39,40</sup> and this has important implications for the accuracy of clinical trial data. With medications such as anti-TNF therapies that can have a dramatic impact on patients' disease state (in terms of speed and magnitude), it is imperative to include outcome measures on response shift to determine true treatment effectiveness. The change in adaptation over time is also important to study as more knowledge could help us understand what patients' answers to well-being instruments really mean.

There is a large literature on depression in RA,<sup>13</sup> and, although this is an important clinical outcome, it is a narrow indicator of the psychological well-being considered important by patients in this study. The International Classification for Functioning, Health and Disability (ICF) core set for RA, an influential framework for assessment, is also limited in its potential for assessing psychological impact. With the exception of 'Emotional functions (b152) and 'Experience of self and time functions' (b180) in the ICF body functions component, there are no items in the ICF core set that appear to capture the broad range of psychological responses in the 'Being in the mind' or 'Adapting to illness' themes

raised by this study. In a study of occupational therapy practice in nine countries, Kirchberger et al. also found that psychological elements were missing in the ICF RA core set, including self-confidence, relaxation and psychosocial well-being.<sup>42</sup> It is important that the current process of classification of the ICF personal factors component incorporates the psychological aspects of (un)wellness important to patients. Contextual factors were another important influence on well-being in this study, and the ICF core set for RA does contain a comprehensive environmental factors component, which includes ‘Societal attitudes’ (e460), ‘Health professionals’ (e355) and ‘Health services, systems and policies’ (e580).<sup>41</sup> However, instruments have not been specified with which to measure these components.

### **Implications for policy**

The findings of this study suggest that the NHS proposal to co-ordinate care with other services is appropriate for LTCs such as RA, where achievement broader well-being may be feasible. Therefore, it is proper in policy documents to separate the concepts of health and well-being. However, consideration should be given to how health professionals can be supported in tackling these broader barriers to well-being, such as housing or employment issues. Within the clinical setting, patients appear to desire interventions that target psychological well-being, including those that facilitate adaptation. Clinical psychologists, educational programmes and other non-pharmacological interventions may best address the psychological issues highlighted in this study (e.g. self-worth, confidence, introversion). Interventions, such as professionally-led cognitive behavioural therapy,<sup>43</sup> or the peer-led Chronic Disease Self-Management Program<sup>44</sup> have also been shown to facilitate response shift.

Given the importance of psychological components to patients, it could be argued that these should be assessed routinely alongside more traditional RA measures of disease activity in clinical trials and in the assessment of eligibility for medications such as anti-TNF therapies. These expensive therapies require fulfilment of strict criteria of consistently high disease activity and previous failure of other disease modifying drugs.<sup>10</sup> There is a risk that current guidelines for access to such treatments may exclude impact criteria important to patients’ well-being.

This study has strengths and weaknesses. A limitation is that all interviews were conducted with RA patients from one UK hospital, which may provide a distinctive type of care. In addition, the numbers on each type of medication, and with experience of discontinuing or switching anti-TNF therapies, are small. However, it appears that the concept of well-being is relevant across medication types and disease activity levels. Another limitation is that recruitment of patients from ethnic minority groups was difficult, with only one interviewee being from a non-white population. Further research is being conducted to determine whether the understanding of feeling well generated here is applicable to a non-Western culture. A strength is that the in-depth interviews enabled a detailed understanding of the way in which people with RA conceptualise well-being in the context of their chronic illness. They also highlight the importance of considering patients' adaptation and context. The study provides the patient perspective on what constitutes well-being in RA and a framework for the different dimensions of well-being to be assessed by clinicians and researchers.

## **Conclusion**

People with RA understand well-being to be the result of a complex interaction between physical, psychological, adaptational and contextual factors. This study describes what well-being *might be* for people with diverse experience of RA, and signals the process by which it may be *achieved*. Addressing the processes inherent in experiencing and constructing well-being in the context of a LTC will improve the accuracy of outcome measurement and interventions relevant to patients. This process-orientated approach to a complex outcome that is important to patients provides health professionals with an insight into how pharmacological treatment may be only one type of intervention for improving their patients' well-being. The findings indicate the possibility of wellness in RA, and potentially for other chronic conditions characterized by chronic pain, fatigue or disability.



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**Table 1: Interview schedule**

1. Tell me about your health.....
2. What is important in terms of your health?
3. How do you know when a treatment is working?
4. Other patients have talked about 'returning to normal'. What does that mean to you?
5. What makes you feel well (or better)?
6. Other patients have described finding benefits from having rheumatoid arthritis. What benefits have you experienced (if any)?

**Table 2: Demographic details of patients interviewed**

Patient code	Age (yrs)	Gender	Work status	Disease duration (yrs)	Current medication (discontinued)	HAQ†	DAS global ††	% Well-being
AA	53	Male	Carer	10	Et	0.625	5.1	50
AB	69	Female	Retired	9	(In)	1.375	1.3	70
AC	50	Female	Retired	17	Et	1.750	2.6	80
AE	69	Female	Incapacity	40	In	1.875	1.2	80
AF	65	Male	Work (FT)	40	In	0.000	2.6	80
AG	42	Female	Work (PT)	19	(In, Et, Ad)	1.500	0.7	90
AH	27	Female	Unemployed	18	Et	1.250	2.3	65
AI	74	Male	Retired	27	In	0.000	1.3	90
AK	54	Male	Work (PT)	9	Et	0.000	1.6	85
AL	72	Female	Retired	19	Et(In)	1.625	6.3	70
AM	35	Female	Incapacity	4	(In, Et, Ad)	2.375	7.4	20
AN	48	Female	Homemaker	19	Ad (In, Et)	2.125	8.2	90
AO	59	Female	Incapacity	9	In	1.625	9.7	5
AP	60	Female	Retired	5	Ad	1.125	3.6	98
AQ	52	Female	Work (PT)	15	(Et)	1.000	2.2	60
AR	70	Female	Retired	32	Ad (Et)	2.625	7.5	50
AS	67	Female	Retired	27	In	1.375	4.9	50
AT	65	Female	Work (PT)	6	Methotrexate	1.250	1.2	75
AU	70	Female	Retired	6	Methotrexate	0.000	2.4	70
AV	74	Female	Retired	39	Sulphasalazine	1.875	4.8	80
AX	79	Male	Retired	31	Sulphasalazine	0.000	1.3	100
AY	52	Female	Incapacity	38	Methotrexate	0.875	3.3	50
AZ	53	Female	Incapacity	3	Sulphasalazine	2.500	3.5	40

Et=Etanercept; In=Infliximab; Ad=Adalimumab

† HAQ score 0 – 3 (3 is most disabled)

†† DAS patient global VAS 0 – 10 cm (0 = doing very well, 10 = doing very badly)

**Table 3: Vignette of feeling well as a process**

Melissa (AN) was diagnosed 19 years ago, at 29, and she “naively thought it would be a few aches and pains, and I would carry on as normal”. Different medications were trialled with little benefit, but lots of side effects. She described a low point in hospital: “I am not living; I’m just existing and I’m in so much pain most of the time.”

She was a working mother of a young child and says the RA did “change my sense of identity because I had to stop work as a therapist. I had felt I was contributing something worthwhile to society” She remembered thinking “But now, what use am I, I can't even be a proper mother?”

Melissa began to accept the condition and benefit from treatment from the multidisciplinary team: “I have to be careful not to overdo it. The physio[therapist] gave me permission to rest.” She reflected on the personal growth since the diagnosis: “When you're ill, you have more time to think, sort out what is important.” She continued: “I learnt that although we often define ourselves by our roles in life, when you can no longer do some of these things, you are more reliant on the person within.”

She was able to differentiate between her symptoms and overall wellness: “I would define ‘feeling normal’ as being well. It doesn’t always mean that if my arthritis is bad I get down about it”. She had reconceptualised normality to incorporate the RA. In Melissa’s case, her sense of connectedness to others and to God was crucial in creating a sense of well-being: “I’ve really been amazed and impressed by other people and the way that they have been so kind when I’ve needed it.”

**Figure 1: The dimensions contributing to feeling well for RA patients**

