Published in final edited form as:

Musculoskeletal Care. 2009 September ; 7(3): 194–209. doi:10.1002/msc.149.

The impact of patient-perceived restricted access to anti-TNF therapy for rheumatoid arthritis: a qualitative study

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Abstract

Objective—To explore rheumatoid arthritis patients' experience of access to anti-TNF therapy in the UK, and of switching therapies after an initial failure.

Methods—Patients were asked about their experience of accessing, receiving and discontinuing anti-TNF therapy in face-to-face informal interviews, within the context of the larger study about treatment outcomes. 17 individuals with a diagnosis of rheumatoid arthritis and experience of receiving anti-TNF therapy were interviewed in one hospital trust in England.

Results—Different emotions (Theme 1) surrounded the process of accessing anti-TNF therapy: hope, desperation, apprehension, anxiety, and frustration. Experience of receiving anti-TNF therapy (Theme 2) included not only positive transformation, but also fear of failure and discontinuation. The subsequent value that patients placed on anti-TNF therapy (Theme 3) included having a right to receive therapy and being lucky. These three themes were underpinned by the core category of 'willing to try anything'. Those switching therapies reported increased caution over the possibility of recurring side effects, but some suggestion of benefit. There was a perception that access to anti-TNF therapy was restricted by cost, rather than being recommended for those in clinical need.

Conclusions—Anti-TNF therapies may have a sudden and dramatic impact on RA patients' lives that contrasts with other available medications. However, the stress of the patient's journey through the need to "qualify" for anti-TNF therapy, and the fear of failing or discontinuation of therapy should not be underestimated by clinicians.

Introduction

Anti-tumour necrosis factor (anti-TNF) therapy has been shown to be effective in the treatment of rheumatoid arthritis (RA) in randomized controlled trials and clinical practice (Blumenauer et al., 2002; Blumenauer et al., 2003; Navarro-Sarabia et al. 2005). In the UK, the National Institute for Clinical Excellence (NICE) recommends anti-TNF therapy for use in the NHS for patients who have evidence of clinical need. The level of clinical need has been agreed with the British Society for Rheumatology (BSR) as sustained inflammation over four weeks plus failure of at least two standard drugs (NICE, 2007). Switching patients to another anti-TNF therapy if the first is poorly tolerated or lacks efficacy is standard practice (Keystone, 2006), but there is mixed evidence for this strategy (Buch and Emery,

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Ethics approval: Bath research ethics committee (07/Q2001/30)

2006; Gomez-Reino and Carmona, 2006; Villeneuve and Haraoui, 2006; Subrahmanyam et al., 2008). Hyrich and colleagues reported a significant improvement in disability (Health Assessment Questionnaire, HAQ) in patients who switch to a second anti-TNF, providing an effective next choice of therapy for some patients who fail to respond to their first anti-TNF (Hyrich et al., 2008). NICE's recent appraisal document on the sequential use of anti-TNF therapy proposed that "Adalimumab, etanercept and infliximab, within their licensed indications, are not recommended for the treatment of rheumatoid arthritis after the failure of a TNF-alpha inhibitor" (NICE, 2008a). However, this has been successfully appealed and the appraisal may be restarted (NICE, 2008b). Response from patient groups was that this proposal would have withdrawn potentially effective treatment from those who have inadequately responded to a first therapy: "NICE is systematically taking away clinically effective and proven treatments from patients and giving them just one roll of the dice when it comes to Anti-TNF treatment" (National Rheumatoid Arthritis Society (NRAS), 2008).

Studies have shown that some rheumatologists have been unable to prescribe anti-TNF therapy to all RA patients who meet the NICE guidelines. Of 148 rheumatology units across the UK who responded to a survey, 31% of doctors were unable to provide treatment to all qualifying patients, more than 50% citing lack of funding as the reason (PN News, 2005). This translated as nearly 1,700 eligible RA patients not gaining access to treatment. In 2006, 46% of 115 consultants who completed a questionnaire about UK anti-TNF therapy use indicated that they had some form of limitation in prescribing anti-TNF therapy to eligible patients; the main reasons being capped funding or numbers of patients (Kay and Griffiths, 2006). However, there are no up-to-date studies and anecdotally many rheumatologists report little difficulty with funding, provided patients meet the clinical criteria of need.

The Disease Activity Score (DAS) is the evidence of clinical need used, and is a composite score derived from the number of tender joints, swollen joints, circulating inflammatory markers, and patient opinion (Van der Heijde et al., 1993). However, previous qualitative research suggests the patient perspective is not fully captured by these conventional tools (Carr et al., 2003; Hewlett et al., 2005; Ahlmen et al., 2005). Two qualitative studies have focused on the patient experience of a first anti-TNF therapy. In the first study, focus groups elicited five themes: expectations of treatment; experience of treatment and its effects; concerns about taking a new class of drug; views about the BSR Biologics Registry process; and cost (Marshall et al., 2004). Participants were first time users of anti-TNF therapy and the effect of trialling more than one therapy was not addressed. In the second study, four main themes were identified: the impact of living with RA; the influence of anti-TNF therapy on physical, psychological and social function; the experience of attending for treatment; and the impact of discontinuing treatment (Edwards, 2004). However, all participants were in a clinical trial with planned cessation of infliximab after six months, which differs from its use in clinical practice.

The overall aim of our larger study was to elicit and explore treatment outcomes with RA patients in order to develop a patient-generated core set of measures. During 23 interviews many patients spontaneously and frequently raised issues relating to perceived restricted access to anti-TNF therapy, which were further explored. This paper reports the experience of anti-TNF therapy from those 17 patients who had received one or more anti-TNF therapies.

Method

Sampling and recruitment

All patients who had received anti-TNF therapy treatment in the rheumatology unit of a university hospital were invited to participate, irrespective of whether treatment was current

or discontinued. In this Trust, all patients who fulfil the clinical criteria and are put forward for therapy are automatically funded for anti-TNF therapy. From those who indicated an interest in the study, patients were purposively sampled for a range of disease duration, disease activity (self-reported on a Visual Analogue Scale), age, work status, gender, and disability (Health Assessment Questionnaire; Fries et al., 1980).

Individual interviews

Ethics approval was obtained, patients were assured of the confidentiality of the data, and then patients gave written consent for participation. The interviewer (TS) used a topic guide devised from a literature review, to prompt discussions about treatment outcomes, well-being and their relation to therapy, followed by open questions to explore the patients' responses further (Box 1). Interviews were tape recorded and transcribed verbatim. Data saturation was determined when the interview responses of the final participants fitted within the emergent coding scheme.

Box 1 Interview topic guide

- Tell me about your health.....
- What is important in terms of your health?
- How do you know when a treatment is working? What is different about receiving anti-TNF therapy from other medications?
- Other patients have talked about 'returning to normal'. What does that mean to you?
- What does feeling better mean to you? What does well-being mean to you?
- Can you tell me about any positive experiences from having rheumatoid arthritis?

Data analysis

A Grounded Theory (GT) approach was taken to data collection and analysis, requiring that the findings be grounded in the data and patients' own words (Strauss and Corbin, 2003). Data were analysed using systematic coding and managed using NVivo 2 software. Transcripts of interviews were reviewed and initial codes identified across the broad range of topics, then categories, themes (major categories) and an overall theme (core category) were formed according to Corbin and Strauss' guidelines (2003). Coding by TS was peer reviewed by SH, MM and PR. In addition, data were analysed using Framework (Ritchie and Lewis, 2003), which followed the participants' individual journeys. Following this, analysis focused on the emergent codes and thematic categories that related to the perceptions of access to anti-TNF therapy for those with experience of it (17 of the 23 interviewed for the larger study), and which are reported here.

Results

13 patients currently on anti-TNF therapy (etanercept, 4; infliximab, 5; adalimumab, 4) and 4 who had permanently discontinued anti-TNF therapy were interviewed (Table 1). Identified categories could be organised into the model illustrated in Figure 1. The results are presented as three themes: emotions surrounding perceived restricted access to anti-TNF therapy, diverse experiences of anti-TNF therapy, and placing a value on anti-TNF therapy, underpinned by the core category of 'willing to try anything' (Figure 1).

Theme 1: Emotions surrounding restricted access to anti-TNF therapy

There were five categories surrounding the process of accessing anti-TNF therapy: hope, desperation, apprehension, anxiety, and frustration. **Hope** and **desperation** were common narratives and were closely linked by the feeling that this medication would be their ‘last chance’ (Box 2).

Apprehension about the possible side effects made a few participants question whether they had made the right decision to be considered for anti-TNF therapy, and some delayed starting treatment. This apprehension was counterbalanced by both the desperation mentioned above and by lengthy consideration by patients about the risks. The severity of the impact of RA and failure of other disease modifying drugs meant that patients were ‘willing to try anything’. Consequently, the need to “qualify” and the perception of restricted access to medications resulted in **anxiety**.

Other patients described **frustration** and anger at trying to access the therapy. Although some female participants described ‘fighting’ for what they wanted in relation to other medications and treatments, it was the male participants who reported actively pursuing access to anti-TNF therapy. Both anxiety and frustration centred around the concept of ‘not being bad enough’.

Box 2 Emotions surrounding restricted access to anti-TNF therapy

Hope and desperation

- “I was, you know, hoping against hope that it would work.” (AG)
- “You’re in limbo while you’re waiting and it does make you feel as though this is the end.” (AC)
- “I came to the end of the line ... it was bleak.” (AI)

Apprehension

- “I was very clearly told all the side-effects by the hospital. I hummed and aahed for about two weeks. [...] I didn’t know if I was making a huge mistake...” (AH)
- “I was a little bit wary because you don’t know what the long-term effects are.” (AP)

Anxiety

- “I don’t know whether feeling rotten was due to arthritis or waiting for the decision.” (AL)
- “We had to have two blood counts done... sent away... to see how high... how bad your arthritis was and they both came back that they were very high. So I was accepted. But you’ve got to be accepted by the Board. I thought: What if it comes back that I’m not bad enough for it ...” (AE)

Frustration

- “They said no you can’t have it because you’re not ill enough and I said to Dr [X] well I ain’t going to bother coming any more because it’s just a waste of time.” (AA)
- “I was angry at the time because I knew that this treatment was available but I wasn’t eligible for it. I was frustrated and wrote to the Department of Health and my MP. I thought: There’s a treatment that could potentially really help and

could stop further joint damage and allow me to keep working, but I can't get it." (AK)

Theme 2: Diverse experiences of anti-TNF therapy

There was a range of experiences once on anti-TNF therapy, some continuing the theme of perceived restricted access, including anxiety about administering the therapies, increased support, positive transformation, measured change, side effects, disappointment, and fear of ceasing treatment. There was **anxiety** related to the practicalities of taking the therapy and the idea of 'being tied' long term to 'heavy drugs' or 'to a machine' (Box 3). Many participants who were self-injecting etanercept or adalimumab did not like the idea of being "hooked up" to the intravenous therapy (infliximab). Whilst some participants who were self-injecting reported initial anxiety, in most cases specialist nurses were able to overcome these fears and the new 'pens' were praised for being easy to use. Increased contact with and **increased support** from health professionals was also appreciated.

Patients who were responding positively to therapy gave enthusiastic descriptions of the **positive transformation** on their lives, including a sense of newness and return to normality. However, there were a similar number of descriptions that were more measured. In some instances this was due to the irreversible joint damage and other health problems.

There was a similar mixture of responses from those taking anti-TNF therapy for the first time, whether it was etanercept, infliximab or adalimumab. Those on a second or third type of anti-TNF therapy tended to be more cautious about possible improvements in the light of previous side effects or lack of response. However, there were also examples where the second therapy proved to be effective.

Seven interviewees who had discontinued one or more anti-TNF therapies (four permanently discontinued), described how the **side effects**, and the associated stress of coping with them, outweighed the benefits (Box 3). Despite the gravity of the side effects, all four patients who had permanently discontinued anti-TNF therapy described their huge disappointment at not being able to continue it. Feelings of **disappointment** were raised by all participants who had not responded. Part of this was due to reaching 'the end of the road' in terms of medication as described earlier, but it may also be related to a belief generated by **media stories** that expensive treatment is more likely to be effective.

Those who had responded well to anti-TNF therapy were also anxious and **feared being taken off therapy** because they no longer needed it. They were anxious therefore about appearing too well, reluctant to talk about side effects and retained the memory of previous failed attempts.

Box 3 Experience of receiving anti-TNF therapies

Anxiety

- "I was apprehensive about being hooked up. I had a funny turn when they were ready to hook me up." (AL)
- "I don't want to spend a day up here on a machine anyway" (AC)

Increased support

- "There's just that bit more support with Dr [X] and the nurses" (AA)
- "Every 3 months I have an appointment with the anti-TNF nurse so I can ask if there's any news." (AH)

Positive transformation

- “The initial response was amazing, incredible... I’m so much better, if not 100%..... it’s certainly improved things.” (AK)
- “I was one of the real success stories, it worked wonderfully well.” (AB)
- “It’s like a new world.” (AA)
- “I have a new lease on life.” (AE)
- “It’s completely changed my life, everything is different.” (AF)

Measured change

- “Anti-TNF did improve things because I was getting quite housebound. I’ve got my life back to a degree.” (AL)
- “I feel that I’ve come out of it, the nightmare The anti-TNF has helped me, very much [...] but it’s not got rid of everything at all, just made it more manageable.” (AH)

Caution about switching

- “I was really disappointed when the infliximab didn’t work. I was wary then about injecting Humira alone if I had the same reaction.” (AG)
- “Remicade worked really well for nearly three years... But then it just stopped working completely and I had a huge flare-up early last year. They changed me onto etanercept... unfortunately it started to affect my eyes and so... and since then I’ve had a really rocky road because they put me on the humira and ... so at the moment I’m still on it and we will see.” (AN)

Effective as second therapies

- “So far it’s been all right on Enbrel. [...] Now my heart problem seems to stop me more than the arthritis” (AL, first therapy infliximab)
- “It [Enbrel] wasn’t working. My hands swelled and... you know... I had a lot of pain. [...] On Humira, you find you can start doing some of these things, it brings you out of yourself... you do feel better and you feel more healthy.” (AR)

Side effects and associated emotions

- “The anti-TNF did help me a little bit but it started to get so bad, I couldn’t do anything. It made me really moody, I was snapping at the children all the time and I found I was getting things like mouth ulcers and my tummy was constantly sore and then I had to stop it.” (AM)
- “I had a bad reaction on the third injection of Remicade, then went onto Humira and was brilliant for the first month. Then it stopped working. [...] In the second injection I got very hot, pains around my kidneys, really sore and had difficulty breathing.” (AG)

Disappointment

- “[My expectations] were not too high for two reasons: I was one of the early ones who went on, and I know two of them had to come off it because of problems. [...] Obviously I was disappointed when I had to stop.” (AB)

- “I found it distressing to be taken off Enbrel injections while I had the chest infection. It was like going from the heights of getting somewhere to the depths of despair, knowing that I would get worse.” (AQ)

Media influence

- “My family were absolutely delighted because there was also all this going on in the press about how it’s really expensive. When you read stories in the press [...] we only ever see the good ones.” (AG)

Fear of ceasing therapy

- “I think I’d kill for it now. If it has this sort of effect on you. I don’t like to say anything to the nurse in case she says this is your last.” (AF)
- “I suppose it would be nice to know that the treatment isn’t going to be withdrawn.” (AK)

Theme 3: Placing a value on anti-TNF therapy

There were two types of valuation given to therapy: the monetary cost and the effectiveness or trade-off cost. Patients reacted to the monetary cost of treatment in different ways: that it was their right to receive it, feeling lucky, and, for those who were self-injecting, the expense resulted in a sense of personal responsibility. Patients defended their **right to receive the expensive treatment** either due to their National Insurance contributions or their clinical need (Box 4). One participant was so desperate to try it, that he considered finding the money himself.

In light of this, most participants described how **lucky** they felt to be receiving anti-TNF therapy. In contrast, for one person who was experiencing significant side effects the cost was another reason to stop: “I’d rather give it to someone that it’s going to work” (AM). For those self-injecting, the cost became a **personal responsibility** which had an emotional consequence when having difficulty administering the therapy. For some patients, improvement in well-being even seemed to override concerns about side effects, suggesting a **trade-off** of the value of overall improvement outweighed potential side effects. The data illustrate a complex set of reactions to gaining access to and experiencing anti-TNF therapy. Taken together the three themes formed an underlying core category of being ‘willing to try anything’, leading to intense emotional responses and valuations of anti-TNF therapy:

“The gold [injection] was expensive and I was getting constant flare-ups, constant pain. The methotrexate... that got a reaction with the sun. [...] That’s when they decided to try me on this stuff, the Humira. I thought: “I’m willing to try anything.” (AP)

Box 4 Placing a value on anti-TNF therapy: monetary & effectiveness valuations

Right to receive anti-TNF therapy

- “I paid National Insurance all my life... So I think it’s time I got my ... well, it’s my dues.” (AP)
- “A friend of mine said: “Look, why don’t you borrow the money, fund it for the three months to see whether it works and if it works then we’ll draw up some sort of game-plan...” (AK)

- “I think in some places its one of these postcode lotteries things, which I think it awful really, I mean if there’s a need, a medical need then I think you should be sort of entitled to it” (AI)

Feeling lucky

- “Gosh... I mean £350 [per injection]. I say to my husband: “I’m very lucky to be put on it”, because I think without it I wouldn’t be sat here or walking” (AR)
- “I’m very grateful to be given it as it’s a horribly expensive drug.” (AS)

Personal responsibility

- “I think the worst thing about etanercept so far is that when I’ve done it wrong and I’ve lost the drug and I think cor all that money down the drain.” (AA)
- “You sit there and try and get every single drop out of, and then you make sure that the syringe, you really press it and try to squeeze the bit down to make sure you’ve got every drop. But it does I mean it is precious because it’s expensive.” (AC)

Trade-off

- “I’m quite happy on Humira. And if they said that it’s affecting my other organs I’d say: “Well, I’m staying on it because I’d rather do that”.” (AR)

DISCUSSION

Within a study on outcomes of treatment important to patients, accounts of the intense experiences of accessing anti-TNF therapy were spontaneously raised by patients. Three main areas relating to access emerged: the emotions associated with accessing and receiving anti-TNF therapy, the experience of receiving it, and placing a value on the treatment. The high expectations and successes of anti-TNF therapy have previously been reported (Edwards, 2004; Marshall et al., 2004), but this research shows a more complex clinical picture including the potentially negative psychological impact of perceived restricted access to a medication, even for those who are responding positively to treatment. The underpinning core category ‘willing to try anything’ reinforces the severity of symptoms that patients eligible for anti-TNF therapy experience. The hope of improvement from anti-TNF therapy was tempered by desperation (perceptions that it was a last resort), of apprehension about the treatment, and anxiety and frustration about gaining access to it. Chilton and Collectt (2008) reported that RA patients demonstrated a clear treatment preference around anti-TNF therapy and many wish to share in treatment decisions.

Our data also revealed the value placed on anti-TNF treatment: a value that is constructed from the knowledge of the cost, perceived restricted access, and of the need to have their clinical criteria discussed by the clinical team. This resulted in different patient responses including: having a right to treatment, being lucky, and having a personal responsibility. An Australian study similarly found that stakeholders’ (including patients and clinicians) specific concerns about TNF inhibitors were the contentious cases of individual RA patients being denied access, as well as the timeliness of access, the bureaucracy of the process, and insufficient patient information (Lu, 2007). This paper raises three issues for debate, which although arising in a rheumatology context, may be applicable in other clinical situations.

Recommendation versus restriction

First is the issue of recommendation, which is perceived by patients as restriction. Patients’ feelings around not being “bad enough” or not being eligible, indicate that patients may

misconstrue the NICE *recommendation* of therapy for those in whom it should work, as a *restriction* for all of the patients. Health care resources are not unlimited, therefore there is a societal duty to attempt to spend limited funds effectively and fairly. By reviewing evidence of efficacy for the biologic agents and then recommending their use for those in whom the evidence suggests they are likely to produce a worthwhile improvement, NICE is attempting to fulfil those dual aims. The NICE recommendation that drugs ought to be provided is a significant factor in helping clinicians obtain funding, yet it is perceived as restriction, rather than facilitation, by patients.

The media and access to the Internet frequently influenced the patient expectation of dramatic improvement on anti-TNF therapy. A study of online support groups for breast cancer, arthritis and fibromyalgia suggests that information about medication and treatment protocols are shared amongst patients, even enabling some patients to qualify for a specific type of therapy such as Herceptin for breast cancer (Van Uden-Kran et al., 2008). Clinicians may underestimate the effect of on-line forums, the media, language, desperation and hope on some patients' perception of access to anti-TNF therapy.

Patients' perception of clinical need

Second is the issue of drugs being offered to those in clinical need, which is perceived by patients as having to 'qualify.' This study highlights the potential for psychological distress when a patient's perspective of experiencing "bad" RA is still not "officially" bad enough to meet the NICE recommendations for access to therapy. This may create the unusual situation where patients want to be found as having "really bad" RA. This research was set within a Trust where those who have been put forward for therapy have always been funded. However, this may be an effect of clinicians only proposing patients whom they are certain will meet NICE criteria, which may represent a form of conscious or subconscious pre-screening (rationing). It is not known whether rheumatologists in other Trusts are still restricted by limited resources nationwide as the last published survey was in 2006 (Kay and Griffiths, 2006). Clinical rationing on the basis of age in a number of other conditions such as end-stage renal dialysis (Varekamp et al., 1998) and myocardial infarction (Elder and Fox, 1992) has been shown, but as yet there are no data on whether this is the case in RA. However, it is possible that the policies in individual Trusts are not transparent to or understood by their patients.

A 'worthwhile' response?

Third is the issue of a worthwhile improvement in patients who are 'willing to try anything'. Current evidence is that anti-TNF therapy is effective in those with high levels of inflammation (i.e. 'worthwhile' improvement), leading to NICE recommendation for funding (Blumenauer et al., 2002; Blumenauer et al., 2003; Navarro-Sarabia et al. 2005). However, patient perceptions of a worthwhile response may be different, influenced by different outcomes and priorities from clinicians. Even small improvements may be noticeable by patients, set within the context that they are "willing to try anything" because the outlook is "bleak" and they're at the "end of the line". Until larger trials looking at the efficacy of anti-TNF therapy with lower levels of disease, or earlier use in the treatment plan, are published, it is not possible to know if the criteria for clinical need could be broadened (Baumgartner et al., 2004; Breedveld et al., 2004; Genovese et al., 2002). Therefore, issues such as a 'worthwhile' response to therapy need to be discussed explicitly with patients (Kaye et al., 2006).

These three factors combine to make patients desperate, particularly as there is a perception that their options may be diminishing as the evidence for sequential use of anti-TNF therapies is still under review by NICE (2008b). Desperation has been illustrated through

patients considering raising funds themselves, worrying about being taken off therapy, not reporting side effects, and being willing to take risks that they deem acceptable in the face of their symptoms. Camouflaging of infections has been previously reported, with 27% of patients not withholding anti-TNF therapy during an infective episode and several reporting that they tried to camouflage infections (Dziadzio et al., 2007). Our data also provide new insight into the disappointment of discontinuing therapy and the uncertainty of moving from a failed therapy to an alternative one. Psychological support for people with RA is a current NICE recommendation (NICE, 2008b) and rheumatology units may need to consider the resources available for psychologically supporting patients in these contexts.

Strengths and limitations

This study conducted interviews with a more diverse group of anti-TNF therapy patients than previous studies, including those who were receiving adalimumab and those who had switched therapies. However, the numbers on each type of therapy remain small. Another limitation is that this study was conducted in a single centre and other centres may have different policies surrounding anti-TNF referral, being served by different Primary Care Trusts (PCT) with different priorities and budgets. The concept of “restriction” may present differently in other centres: for example, at the level of the patient/clinical interface (as in this unit) or at the PCT / administrative level. A multi-centre study including clinicians and Trust administrators could explore these issues.

There was an initial reluctance for participants to speak negatively about their treatment, perhaps because they perceived that they had received good care, or out of respect for their health professionals. Whilst it was possible that this may also have been due to a perception that the interview would impact on their care, this is unlikely as the researcher was not involved in clinical care and confidentiality was addressed at the beginning of each interview. It would have been useful to interview patients on several occasions, for example prior to and after starting anti-TNF therapy, to explore whether expectations and beliefs about the treatment had changed. Further work could also include an examination of clinicians’ language around anti-TNF therapy (e.g. use of “qualify”), alongside the access procedures.

Conclusion

This research shows how the process of ‘qualifying’ for and receiving a treatment that is perceived as being restricted, whether by cost or other factors, can affect the well-being of patients. Even when anti-TNF therapy has been prescribed and appears to be effective, this study shows that anxiety may remain about continued access to a ‘restricted’ treatment. The original NICE appraisal about the use of sequential therapies created an emotional response from patients and their representatives (Arthritis and Musculoskeletal Alliance (ARMA), 2008; Arthritis Research Campaign, 2008) and a new appraisal may increase feelings of uncertainty. Clinicians should be aware of the psychological impact of the process for accessing anti-TNF therapy, and address patient fears and anxieties accordingly.

Acknowledgments

The authors would like to thank the participants who took part in interviews and the Arthritis Research Campaign for funding.

Funding: This study was funded by an Arthritis Research Campaign PhD studentship, Grant no. 17439.

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Figure 1.

Impact of perceived restricted access to anti-TNF therapy for RA patients in the UK

TABLE 1

Demographic details of patients interviewed

Patient code	Age (yr)	Gender	Disease duration (yr)	Current anti-TNF (discontinued)	HAQ [†]	DAS global ^{††}
AA	53	Male	10	Et	0.625	5.1
AB	69	Female	9	(In)	1.375	1.3
AC	50	Female	17	Et	1.75	2.6
AE	69	Female	40	In	1.875	1.2
AF	65	Male	40	In	0	2.6
AG	42	Female	19	(In, Et, Ad)	1.5	0.7
AH	27	Female	18	Et	1.25	2.3
AI	74	Male	27	In	0	1.3
AK	54	Male	9	Et	0	1.6
AL	72	Female	19	Et (In)	1.625	6.3
AM	35	Female	4	(In, Et, Ad)	2.375	7.4
AN	48	Female	19	Ad (In, Et)	2.125	8.2
AO	59	Female	9	In	1.625	9.7
AP	60	Female	5	Ad	1.125	3.6
AQ	52	Female	15	(Et)	1	2.2
AR	70	Female	32	Ad (Et)	2.625	7.5
AS	67	Female	27	In	1.375	4.9

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)