An investigation into the experiences of occupational gain in people with inflammatory arthritis receiving antiTNFα treatment

Grant holder
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Introduction

The aim of this exploratory study was to develop an in-depth understanding of the experience of occupational gain in people with inflammatory arthritis receiving anti-TNFα treatment and to use that understanding to explore the implications for occupational therapy practice.

Rheumatoid Arthritis is a chronic, progressive inflammatory disease with the potential to cause cartilage destruction and bone erosions and affects around 387,000 adults in the UK. People with RA experience problems with leisure, household, social and employment activities; people perform fewer valued activities associated with a higher incidence of depression. Ankylosing Spondylitis affects the sacroiliac joints, axial skeleton, entheses and, occasionally, peripheral (upper and lower limb) joints predominantly impacting on young adults. Patients experience stiffness, pain, fatigue, poor sleep, and express concerns about appearance, worries about the future, adverse medication effects and difficulties with family relationships, sexual function and work.

Historically the disease trajectory of a person with inflammatory arthritis has been characterised by progression of their impairment decline, with increasing levels of biomechanical damage and activity limitation leading to reduced involvement in occupational activities. Tumour necrosis factor (TNFα) plays a crucial role in the development of inflammatory arthritis, promoting inflammation and joint damage. The introduction and increasing use of anti-TNFα treatment over the last ten years has significantly impacted on the management of inflammatory arthritis reducing disease activity and activity limitation and improving quality of life, thus enabling people to move from a trajectory of long term progression to one of maintenance and potential improvement. Occupational therapists face new and interesting questions as the focus of their interventions potentially changes to one of promoting and restoring health and seeking to capitalise, in occupational terms, on the benefits afforded by these new treatments. In developing interventions which are responsive to the needs of service users it is essential that new models of working are informed by the experiences of service users. To date, much of the evidence relating to the efficacy and effectiveness of anti-TNFα treatment is derived from clinical trials and fails to provide a detailed insight into how the clinical benefits of these new treatments translate, at a personal level, into changes in occupational gain.

Current biomedical research work has provided important evidence on the efficacy of anti-TNFα treatments on dampening down the autoimmune response. Other research has provided some insights into the broader impact of these therapies on occupational performance. However this work did not focus specifically on occupational gain or explore the implications for occupational therapy practice.

Method

This qualitative project, influenced by a phenomenological perspective, adopted a case study approach to exploring the issue through service user and service provider viewpoints, within specified boundaries, acknowledging the complexity of social truths. A phenomenological perspective provides a framework from which to gain insights into human occupation. The boundaries of the case are the experiences of people receiving anti-TNFα treatment and the experiences of occupational therapists working with these people.

The project was conducted over twelve months. This allowed sufficient time to recruit, to have prolonged engagement with the topic and undergo comprehensive respondent validation (factors enhancing credibility of the data). It was undertaken in two locations, East Anglia and North West England and involved service users with RA and AS, and rheumatology occupational therapists in each location. The research process chosen for this project is compatible with the guidelines for
producing good quality evaluations, in accordance with the Musculoskeletal Services Framework (DH 2006). This study was a cross sectional study using in-depth interviews and focussed discussions.

**Phase 1**  - in-depth interviews with people living with RA and AS (service users) who have had a positive response to antiTNFα therapies.

**Phase 2** - views of rheumatology specialist occupational therapists (service providers) were collected to enable triangulation of service user data, thereby enhancing the study’s credibility.

**Sample**

**Service users** - purposive sampling of people with RA and AS who had a positive response to antiTNFα treatment was undertaken. The sample was defined by the following rationale: 1) whilst RA and AS share some characteristics they also have distinct differences; 2) the process of occupational gain could be influenced by the duration of treatment, therefore sampling across a spectrum of treatment durations would provide insights into the influence of duration of treatment on occupational gain.

**Service providers** - rheumatology occupational therapists in each location were principally recruited from the College of Occupational Therapists’ Specialist Section in Rheumatology (COTSS-R). The sample was defined by the following criteria: 1) length of experience as an occupational therapist; 2) length of experience working in rheumatology specialism; 3) location of practice

**Recruitment**

Service user recruitment was coordinated by gatekeepers in NHS rheumatology departments. Service provider recruitment was coordinated through COTSS-R. Potential participants completed an Expression of Interest form which facilitated the purposive sampling.

**Service users** - 27 people with inflammatory arthritis were recruited. Those recruited represented a range of gender, age, disease duration and time on antiTNFα profiles.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Rheumatoid Arthritis</th>
<th>Ankylosing spondylitis</th>
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<tbody>
<tr>
<td>Gender</td>
<td>Female 14 Male 5</td>
<td>Female 2 Male 6</td>
</tr>
<tr>
<td>Age (years)</td>
<td>Median 59 Range 21-78</td>
<td>Median 53.5 Range 34-68</td>
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<tr>
<td>Disease duration (years)</td>
<td>Median 8 Range 2-30</td>
<td>Median 12.5 Range 2-20</td>
</tr>
<tr>
<td>Duration of antiTNFα treatment (mths)</td>
<td>Median 14 Range 5-84</td>
<td>Median 33 Range 15-84</td>
</tr>
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</table>

**Service providers** - Seven occupational therapists were recruited. Those recruited were experienced clinicians who mostly worked in the acute sector. Recruitment levels were lower than expected but everything was done within the bounds of what was ethically approved to enhance recruitment. These data provided rich and robust data to triangulate with the service user data.

<table>
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<th>0-5 years</th>
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<th>11-20 years</th>
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<td>4</td>
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<tr>
<td>Clinical context</td>
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<table>
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<th>Community</th>
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<td>6</td>
<td>1</td>
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**Data collection**

**Service user** - data were collected via one-to-one semi-structured interviews. Interviews lasted between 40 and 70 minutes.
Service providers – data were collected primarily through group discussion prompted by vignettes derived from the service users’ experiences of occupational gain and facilitated by the use of core questions

Analysis

The framework of interpretative phenomenological analysis (IPA) guided the exploration of the data. IPA has its roots in health psychology and acknowledges the active role of the researcher in making sense of respondents’ narratives. By analysing within individual texts and across texts it became possible to recognise not only commonalities but also respondents who had distinctly different experiences to others. Recognising and reporting divergent experiences and alternative explanations helped ensure credibility in the findings, increasing trustworthiness. Participants were invited to review the themes identified in their interview (respondent validation) to increase the trustworthiness of the findings.

Ethics

The study adhered to the principles of research governance to protect confidentiality and anonymity, the right of refusal to participate, to provide adequate information to participants to facilitate informed consent, the importance of ethical approval, the assurance of professional conduct and a participant’s right to approve inclusion of illustrative quotes in the final document. No ethical issues arose from the study.

Results

Service user findings

Three themes emerged which captured the meaning of receiving antiTNFα treatment and the subsequent occupational gain experienced by respondents with inflammatory arthritis.

Theme 1:  ‘Where else is there for me to go’ – Starting antiTNFα treatment
Respondents lived with pain and fatigue which affected their occupational roles and identities. They were unable to fulfil the occupational roles of partner, parent, employee and friend; their self-presentation was altered. Many respondents withdrew from social situations because they lacked confidence to participate in activities. They lived every day with the symptoms of pain and fatigue. They experienced failure of a number of other drug treatments and had a fear of the future. It was in this life world that they made decisions to commence antiTNFα treatment. For many respondents the hopes of improvement were tempered by fears about potential side effects. They accepted and started antiTNFα treatment with differing expectations but all reported significant benefits from the treatment.

Theme 2:  ‘I feel like a new person’ – Experiencing occupational gain
There was extensive evidence of occupational gain in all aspects of respondents’ lives. Respondents had opportunities to reclaim and redefine their identities through leisure and productivity activities. There was a period of renegotiation as they tried to re-engage in social relationships from which they had previously withdrawn. They were able to reclaim occupational identities as partner, parent, employee and friend. There was also a process of redefining identities as they were not always able to engage in activities in the same ways they had before, so sporting activities were refocused, hobbies adapted and the level of involvement in employment changed. A few respondents
continued to experience disruptions in their ability to increase participation in occupational activities and this reduced their potential occupational gain.

**Theme 3: ‘I can't do everything I want to’ – Disruption to occupational gain**

Occupational gain was still disrupted by illness intrusions, either due to previous biomechanical damage, continuing symptoms of inflammatory arthritis, or concerns about antiTNFα treatment. These disruptions particularly affected how respondents engaged in productivity tasks, with many people testing new boundaries through a process of trial and error. Hence there was a tentativeness underlying their new self, an overshadowing of continuing symptoms and a high level of uncertainty about the future. Most respondents had not been referred to occupational therapy since starting antiTNFα treatment despite many having continuing symptoms which could have been managed by occupational therapists.

**Occupational therapy findings**

There was a robust level of congruence between the issues raised by the occupational therapists in the focus group and the individual interview and those raised by the service users. The occupational therapist respondents acknowledged the ‘march of the disease’ as a major challenge to living with an inflammatory arthritis. They recognised the challenges to occupational identity and the person’s hope of antiTNFα as a ‘wonder drug’. Within their limited work with people on antiTNFα they were able to appreciate the vignette describing the retention, return and revision of occupational identities but were more surprised about the residual challenges to disrupted occupational gain. Of particular interest to them was the absence of any significant input by occupational therapists in the service user accounts.

The therapists acknowledged that there was still a need for interventions that address the physiological, psychological and biomechanical consequences of inflammatory disease but the changing clinical presentation of people with rheumatological conditions as a consequence of antiTNFα treatment has had an impact on the focus of their interventions. Two superordinate themes emerged from the occupational therapist data: Occupational Therapy Role Development and Promoting the Potential of Occupational Therapy.

**Theme 1: Occupational therapy role development**

The therapists identified that there was a greater emphasis on promoting occupational gain by helping people to explore their occupational choices, to support occupational roles and therefore retain, regain or revise occupational identities. They identified a key role that needed developing was to support people who were responding well to antiTNFα in productivity activities.

The occupational therapists identified that treatment interventions were continuing to develop and the ways in which they worked was changing as people become more stable in their clinical presentations and with less potential joint destruction. It was not that the improved clinical presentation meant that people on antiTNFα medication no longer needed to work with occupational therapists but that there was a continuing move towards an enhanced biopsychosocial lifestyle approach, with therapists adapting their clinical skills.

When considering the theoretical underpinning of their approach to treatment the therapists acknowledged that their biopsychosocial approach enabled them to balance the physiological and biomechanical manifestations of inflammatory diseases against the psychological and social support.
required to try to help patients maximise their occupational performance. This was in contrast to what was seen as a predominantly biomedical approach within the wider service provision. This finding resonates with the service user narratives in which they talked about the primary focus of improvements in clinical markers as a way of measuring their progress on antiTNFα treatment rather than on facilitated occupational gain. The occupational therapist respondents discussed helping to develop the rheumatology team practice into a more comprehensive and coordinated biopsychosocial approach. Working with colleagues such as physiotherapists had enabled some respondents to influence multidisciplinary working particularly in devising lifestyle programmes.

This study recruited both people with AS and RA. The sharing of the experiences of people with AS highlighted to the occupational therapists the ways in which people with AS could benefit from a more multidisciplinary approach. Therapists highlighted that they rarely worked with people with AS because their care was currently predominantly only managed by physiotherapists. This finding is mirrored within the service user data where participants with AS reported minimal occupational therapy intervention despite ongoing needs that would benefit from occupational therapy intervention.

Theme 2: Promoting the potential of occupational therapy

None of the 27 service users had been directly referred to occupational therapy services since they started their antiTNFα medication and yet the findings strongly indicate that they could have benefited from occupational therapy services. There was a general consensus that people were ‘slipping through the net’ and this was a concern for the therapists.

The occupational therapists acknowledged that they needed to work with service users even before they have started their planned antiTNFα regime with a resulting improvement in the timing of their interventions. The occupational therapist respondents did have people on antiTNFα in their caseload but the number did not reflect the expected referral rate when taking into account the number of people on antiTNFα and the potential problems they could be experiencing. The occupational therapists talked about the potential for improving their services for people who were responding to antiTNFα treatment as the service users are still experiencing problems.

Some of the occupational therapists also discussed how their contribution to the rheumatology services may not always be understood fully by colleagues and there was concern that they were missing potential referrals.

The therapists discussed a number of ways in which they had tried to increase appropriate access to occupational therapy services such as contributing to early arthritis clinics, collaborating with other members of the rheumatology team to ensure there was appropriate cross-referral, instigating specific occupational therapy-focussed screening questions to capture people even if an occupational therapist did not attend some of the routine or annual clinics, facilitating service user self-referral and primary care referrals.

Limitations of study

The median disease duration of respondents with RA was 8 years and for respondents with AS was 12.5 years. The likelihood is that they had irreversible biomechanical damage which subsequently affected opportunities to engage in occupational activities. As newly diagnosed patients now move more rapidly on to DMARDs it is possible that the number of people experiencing severe and enduring biomechanical damage may reduce changing the clinical presentation of patients seen in occupational therapy rheumatology units. However increased function prior to starting antiTNFα
treatment may mean that there is increased scope for therapists to maximise occupational gain in these patients.

The experiences of occupational therapists predominantly represent those working within acute NHS Trust hospitals as only one therapist was community based. They also worked within well established multidisciplinary rheumatology outpatients teams having specialist biologics clinics within the department. It is difficult to make claims about practice across the country as therapists were recruited from only three NHS Trusts. The difficulties experienced in this study with recruiting service providers suggest that occupational therapists are currently experiencing many demands on their professional and personal time. Future studies explicitly seeking the experiences of therapists may benefit from developing ethical protocols and research costing which enables recruitment from a larger number of regions. It would be useful in future work to recruit service providers from a wider range of practice setting to enable a comparison of experiences, thereby increasing transferability of findings.

Patients recruited to this study were all in disease remission and were responding effectively to their antiTNFα therapy at the time of their interview, therefore the results capture the experiences of those who are likely to have maximum opportunity for occupational gain.

Discussion

The increasing use of antiTNFα treatment for people with inflammatory arthritis has impacted significantly on the clinical management of RA and AS. While there is a growing evidence base for the clinical efficacy of this treatment there is a need to develop a greater understanding of the personal impact of this treatment to ensure that the clinical benefits are translated into maximum occupational potential.

The findings exposed the ways in which inflammatory arthritis had disrupted occupational performance, impaired occupational engagement, and compromised occupational roles and identities prior to antiTNFα treatment. People approached the new treatment regime with hopes for relief of symptoms and increased function and wellbeing alongside fears about potential side effects of the medication. All respondents experienced improved occupational performance and consequently an increased ability to fulfil important occupational roles within ADL, leisure and productivity domains.

The introduction of antiTNFα treatment was a positive experience for most respondents. The predominantly biomedical approach adopted for the introduction of this new treatment left respondents relying upon their own skills and expertise to manage a number of factors which continued to exert an intrusive and disruptive influence on people’s lives.

The experience of living with inflammatory arthritis

All participants experienced a decline in functional ability over time and an increase in symptoms leading to sustained difficulties in participation in all aspects of life. Decline in physical function impacted on psychological function. There was a decline over time of peoples’ confidence in their abilities to undertake some activities. They adjusted to losses in key areas of activity such as key ADL tasks, withdrawal from the workplace or more physically challenging leisure activities. There was also a reduction in their social activities and networks due to high levels of fatigue. This disruption to occupational engagement for respondents with longer standing disease was experienced for a significant length of time before they were able to access antiTNFα treatment.

Insights from respondents with AS highlighted a distinct difference between the clinical management of RA and AS, where people with AS had very little contact with occupational therapists despite experiencing debilitating functional loss in a wide range of areas of activity.
The experience of living with inflammatory arthritis whilst receiving antiTNFα treatment

This study adds to the existing evidence about the experiences of this group of people through describing the work people needed to do to establish new levels of participation. Data analysis highlighted the challenges they still faced and areas where the potential to maximise on the clinical effectiveness of antiTNFα treatment through occupational therapy interventions are being missed.

The work of establishing a new level of participation

Participants received support from the medical team in the biologics clinic to embark upon and monitor their new treatment regime. People became reliant on monthly blood tests to gain information on their clinical improvement or decline and to monitor side effects. This resulted in health care being located within a predominantly biomedical approach to management.

The impact of treatment on the wider aspects of peoples’ lives was not considered; it was left up to each individual to develop their own response to their changing clinical status. The psychological and social implications raised important questions about the potential to expand occupational engagement into areas which may have been lost for a prolonged period of time. Insights from this study highlight the need to locate management of people embarking upon antiTNFα treatment within a biopsychosocial model to better support people who are increasing engagement in social and productivity tasks and so potentially facilitate occupational gain. The focus of this management could be addressed by occupational therapy interventions to support patients through this process of change.

Changing trajectories: changing occupational narratives

People on antiTNFα treatment experience a changed life trajectory. They have been, and remain, people with a long term condition but now they are on a trajectory of improvement. A changed life trajectory can take time for people to assimilate and adapt to; information needs to be offered in different ways at different times and could be framed within narrative construction. Many respondents continued to situate their narrative of who they are now, within stories of who they had been prior to starting antiTNFα treatment, suggesting that it takes time to redefine one’s identity as a person who is now on a trajectory of improvement and occupational gain.

Using a framework which focuses on narrative reconstruction has the potential to inform work with people experiencing occupational gain to enable them to define new aspirations and plans for the future, to increase their self-confidence and to make the transition to experiencing a lifestyle with fewer limitations imposed by their impairment. This study has highlighted the potential to adopt new ways of working to support people through a transition which has previously not been associated with this area of practice.

Inhibitors to occupational gain

In this study there was evidence that some people were risk-averse to embracing new occupational tasks. This may in part be explained by the way in which self-efficacy was diminished prior to starting treatment. People received minimal advice or support relating to change in lifestyle factors post-antiTNFα treatment; this meant that many used a process of trial and error when increasing participation needing to define their own new boundaries and make significant decisions about, for example, their ability to return to full or part-time employment unsupported. There was evidence of an imbalance with some people over challenging themselves to establish new parameters for their activities and subsequently experiencing pain and fatigue.

Lack of confidence in their own ability and efficacy of the drug was a possible inhibitor in enabling
these people to maximise occupational gain. This lack of confidence was influenced by a past of functional, psychological and social loss. A positive response to AntiTNFα treatment provided the opportunity for the respondents to consider themselves not only in the present time as an increasingly healthy person but also potentially in the future as a person experiencing new events, doing more activities from choice rather than necessity.

People in this study experienced improvement at differing times in their antiTNFα treatment and so therefore may be receptive to interventions at different times. Occupational therapists could provide timely support about realistic occupational choices and ways to achieve these so that people become occupationally fulfilled. Where improvement on medication appears slower than expected education about continued management of symptoms and further advice on the ways in which the drugs work may help to alleviate concerns about efficacy.

Managing challenges

Occupational gain brought with it challenges: expectations about the efficacy of antiTNFα treatment, accommodating continued symptoms of inflammatory arthritis within the context of occupational gain and the expectation of significant others who perceived them as well again.

Limited or misunderstanding of medication appears to have caused some respondents to be concerned about the time it took them to experience occupational gain and their continuing symptoms. Understanding the concern these people had about potentially being taken off medication is important for therapists.

Not all symptoms were relieved by antiTNFα treatment and about a third of the respondents continued to experience biomechanical disruption, fatigue and pain. Previous biomechanical damage, pain and fatigue continued to cause functional difficulties.

Our results indicate differing understanding about the role of exercise in inflammatory arthritis amongst patients. Given the increased emphasis on integrated public health messages into all areas of clinical practice, the increased incidence of cardiovascular disease in people with both RA and AS, and the sedentary lifestyle associated with increased levels of disease activity the reduction in inflammatory process and symptoms provides an opportunity for people to re-engage with increased levels of physical activity. This re-engagement was generally through a process of trial and error. Respondents with AS appeared not to be fully engaged in the exercises important to prevent further ankylosis of the spine. There is an opportunity for occupational therapists to develop work with people with inflammatory arthritis as they experience increased function to further educate on lifestyle changes including different forms of physical activity which continue to protect joint structure whilst maximising general health.

A consequence of improving health and occupational gain was that other people’s expectations of respondents increased. People may benefit from support which empowers them to choose, organise and undertake occupations which are manageable and meaningful to them in their revised life trajectory whilst managing and renegotiating the expectations of others.

Implications for occupational therapy practice

Occupational therapists enable people to accommodate and adapt to new occupational situations but within current rheumatology practice, therapists may more usually be working with people who are experiencing occupational loss. The development of pharmaceutical interventions for inflammatory arthritis creates the need for therapists to review and revisit their therapeutic interventions to support people who are now experiencing occupational gain. Understanding the
narrative construction work which patients receiving antiTNFα treatment undertake highlights the importance for moving away from a biomedical model of management for this group to one which seeks to support them in redefining their aspirations and developing the relevant skills and strategies to make a successful transition into increased levels of occupational engagement.

There appears to be an assumption that becoming well is a trouble-free process but insights from this study have highlighted a number of challenges with which people require support, specifically with regard to defining appropriate goals and aspirations, managing on-going symptoms and capitalising on reduced levels of activity limitations. Insights suggest that key health policy objectives, such as returning to work and promoting increased levels of physical activity and healthier lifestyles are not being capitalised on and people are often left to their own resources and a process of trial and error.

Rheumatology occupational therapists have always played a significant role in supporting lifestyle interventions in people with RA. They have the specialist skills to recognise factors which may be disrupting identity work and they have the interventions to empower patients to move their personal narrative from one of loss to one of gain and potential, thereby maximising potential benefits which could offset the large economic and personal costs associated with this medication.

**Recommendations**

The current biomedical approach to starting antiTNFα treatment assumes that the process of clinical improvement is a relatively trouble-free process. Insights from the study have identified a number of ways in which occupational therapists can contribute to the management of these patients. They can support people to maximise treatment benefit and facilitate engagement in an enhanced occupational profile which not only enables them to fulfil new occupational goals, but also promotes a more physically active lifestyle. Strategies to maximise this client group’s occupational potential include:

1. **Referral pathways**: Improved occupational therapy referral pathways for people with RA and AS on antiTNFα treatment.

2. **Assessment**: Assessment practices that enable treatment goals to be framed within a person’s narrative, developing individualised treatment plans which aim to maximise occupational gain.

3. **Vocational rehabilitation**: Active consideration of work issues with occupational therapists supporting the review and retention of work for those people currently in employment, and the regaining of work for those currently not employed. There is the potential for a further study to evaluate the efficacy of an intervention to support vocational rehabilitation with this client group.

4. **Lifestyle management**: Some people on antiTNFα treatment continue to face challenges to increasing participation because of the sequelae of biomechanical disruption, and continuing fatigue and pain. However the respondents’ functional improvement provides the opportunity for occupational therapists to support these people to achieve healthier and active lifestyles and deliver lifestyle intervention programmes informed by psychological approaches to behaviour change designed to increase self-efficacy and support behaviour change. There is the potential for a further study to develop and evaluate an intervention programme to support this lifestyle management.
Conclusion

Increasingly people with inflammatory arthritis are receiving anti-TNFα treatment, but there is little evidence about their nuanced experiences of treatment within the context of their occupational lives. Currently anti-TNFα treatment is provided within a predominantly biomedical approach. Such an approach assumes that the process of clinical improvement is relatively trouble-free. This study has identified a number of factors which disrupt the health trajectory of people on anti-TNFα treatment, providing robust evidence for the need for occupational therapy interventions.

Rheumatology provision needs to be more closely informed by and aligned with the needs of these service users. A positive response to anti-TNFα treatment provides opportunities for people with inflammatory arthritis to increase their levels of participation in occupational activities. This study is novel in providing insights into the challenges and concerns people have about making lifestyle changes which maximise potential improvement on anti-TNFα treatment. There are factors which may limit opportunities to maximise benefit from what is an expensive treatment option, both economically to the NHS and psychologically to the patient and their family.

Occupational therapists have a wealth of therapeutic skills that would allow them to enable people to maximise occupational gain through lifestyle and symptom management. People with RA and AS would both benefit from more focused occupational therapy interventions addressing the impact of occupational performance on occupational engagement and the resulting challenges to occupational roles and identities. Further research, informed by insights from this project, could develop and then evaluate the effectiveness of an occupational therapy led intervention using psychological approaches to enable people to manage continuing symptoms, maximise their occupational performance and increase their physical activity.

This study is one of the first to provide good quality evaluation of the service users’ experience of receiving anti-TNFα treatment and as such it informs the knowledge base from which therapists can develop and evaluate future interventions for this growing group of rheumatology patients.