An investigation into the experiences of occupational gain in people with inflammatory arthritis receiving anti-TNFα treatment

Key findings

Service user perspectives:
Theme 1: ‘Where else is there for me to go’ – Starting anti-TNFα treatment
Hopes of improvement for many respondents were tempered by fears about potential side effects. They accepted and started anti-TNFα 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.

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 anti-TNFα treatment. Most respondents had not been referred to occupational therapy since starting anti-TNFα treatment.

Occupational therapy perspectives:
Theme 1: Occupational therapy role development
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 needing development was to support people who were responding well to anti-TNFα in productivity activities.

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 anti-TNFα medication. There was a general consensus and concern that people were ‘slipping through the net’.

Project aims
Much of the evidence to date 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.

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

Background
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.
Methodology

This qualitative project, influenced by a phenomenological perspective, adopted a case study approach to exploring the issue through service user and service provider viewpoints, and 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 rheumatoid arthritis (RA) and ankylosing spondylitis (AS), and rheumatology occupational therapists in each location.

Phase 1 - in-depth semi-structured interviews, lasting 40-70 minutes were held with 27 people (service users) living with RA or AS who had experienced a positive response to antiTNFα therapies.

Phase 2 - views of 7 rheumatology specialist occupational therapists (service providers) were collected to enable triangulation of service user data, thereby enhancing the study’s credibility. 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.

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 service users. 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.

Publications


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