Negotiating targets with patients: choice of target in relation to occupational state

Sandra M. Robinson¹ and David J. Walker¹

Abstract

Objectives. Following the recent National Institute for Health and Clinical Excellence guidance on the management of RA, we were interested to see if we could negotiate targets for treatment with patients in routine clinics, how they would express this and whether staying at work would be a target.

Methods. One hundred RA patients were recruited. They were consecutive within clinics, but not all clinics were used. They were asked their understanding of the DAS score and a target for treatment negotiated. Any impact of the RA on their paid employment was then explored.

Results. Four participants were unable to specify a target for their RA. Negotiated targets were expressed as restricted activities and either as maintaining an activity (70) if the disease was stable, or regaining an activity (26) if the treatment was being increased. Targets were walking a distance for 50% of patients; leisure activities for 18%; domestic activities for 17%; work for 14% and personal care for 2%. For the 21 participants currently working, maintaining work was the target for 12, with 1 wishing to regain lost hours. No patient currently not working expressed returning to work as a target. There were some differences in targets between men and women.

Conclusions. Patients are able to negotiate a target for their treatment, expressed as maintaining or regaining a physical activity. Work ceases to be a target once it is lost. Therefore, preventing loss of occupation is likely to be more effective than trying to regain it.

Key words: rheumatoid arthritis, targets, work, activity, leisure, domestic, walking, maintaining, regaining, gender.

Introduction

The setting of targets for treatment is a way of making sure that a longer term view is taken of how a patient is progressing and particularly for the compliant patient who says ‘I’m fine’, but is not. It is a way of adding some more objective rigour to the assessment of whether a patient’s disease is adequately controlled and a way of judging the treatment. It has found favour in RA where adequate control of the disease, rather than cure, is the aim of treatment. Treatment-to-target studies such as Tight Control Of Rheumatoid Arthritis (TICORA) have shown a benefit of using a pre-determined target set as a level of DAS [1].

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The recent National Institute for Health and Clinical Excellence (NICE) guidance for the treatment of RA [2] suggests that a target for treatment should be negotiated and set with each patient. This appears to be a fusion between the idea of treating to a medical target and involving the patient in the setting of the target. We were interested to explore how negotiating a target with patients might play out in practice. We initially interviewed some patients in a qualitative study [3] to seek their views and showed that patients did not understand the DAS [4]. We wondered if patients would understand the DAS now, following the National Rheumatoid Arthritis Society (NRAS) booklet Know Your DAS [5]. Would they express the impact in a different way? Pain is the main symptom of arthritis [6], but it is difficult to see it as a target as patients are not likely to want any pain, and the difficulty of measuring such subjective symptoms would be a problem. Restriction of physical activities was suggested as a possibility, supported by the fact that it is routine when assessing impact to ask ‘What does it stop you doing?’
We were also interested to see if maintenance of paid employment was a target in patients of working age.

Methods

Patients seen in outpatient departments as part of their routine National Health Service (NHS) care, by one consultant, were approached during the consultation to discuss setting a target for their treatment. Clinics were either used for recruitment or not. If a clinic was used then all RA patients in that clinic were approached. There was a preference for clinics that were not too heavily booked. This was done as service evaluation and ethical approval was not thought necessary.

Patients were told that it was now recommended that a target for their treatment was negotiated with them. There may then have been some discussion about targets and where this recommendation had come from. Patients were then asked if they understood what a DAS was. They were further asked what other impacts of disease would make suitable targets and then asked to select a target that was important to them and which could be used to judge whether their treatment was satisfactory. Only if they were unable to come up with a target of their own were suggestions made from the above discussions.

Demographic data and age of onset of the arthritis were collected and patients were asked if they were working at the time of onset of their arthritis. When appropriate, they were further asked what impact the RA had had on their work and whether it had caused early retirement and if so at what time. The data were tabulated and analysed with descriptive statistics.

Results

Targets were negotiated with 100 RA patients over a 6-month period. Average age of patients was 63 years (range 32–86 years). Average disease duration was 15.6 years (range 1–38 years). Forty-four of the participants were of working age, defined as men <66 years and women <60 years. Of these, 21 (48%) were in paid employment.

No patients had any understanding of the DAS and all felt that symptoms such as pain were not appropriate targets. Restricted activities were then discussed. Four patients were unable to negotiate a target. One patient was totally unable to understand the concept of a target. For three patients, symptoms from other conditions predominated (two back pain and one CTS) making a target for the RA redundant.

For the remaining 96, targets were negotiated. It quickly became clear that these fell into categories of ‘maintain an activity’ for those whose RA was stable and who were not seeking greater efficacy, and into ‘regain’ for those who wished to be better and who were having their treatment increased. Seventy participants wished to maintain their current condition and 26 to regain lost activities.

Targets could be categorized as: walking a distance; leisure activities; domestic activities; work and personal care. The results for the whole population are shown in Table 1. Walking a certain distance was the most common choice and the default position for most participants. The biggest differences between maintaining and regaining were for walking and work. Regaining was usually expressed as walking a distance (62%). Twelve patients wished to maintain their work as their target and only one wished to regain it, and this was a lady who was already working and who wanted to re-increase her hours. It would appear that work and functional activities predominate for maintaining targets, whereas regaining targets were more basic activities such as walking.

The targets chosen in the working age participants are shown in Table 2. Numbers for the different types of target were similar, with the exception of work where, because of the narrower age range, work was numerically more important. For the 21 currently working participants, 13 (62%) chose work as their target. For the remaining eight, five chose walking, one chose leisure and two chose domestic activities as their targets.

Reasons for not currently working in those of working age were: early retirement for 15 for whom 11 had retired directly because of their RA. Seven participants were not and would not have been working and described themselves as housewives. One subject was unemployed and was the one who intellectually could not negotiate a target.

<table>
<thead>
<tr>
<th>TABLE 1</th>
<th>Targets chosen to be maintained or regained: whole population</th>
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</thead>
<tbody>
<tr>
<td>Target type</td>
<td>Maintain, n (%)</td>
</tr>
<tr>
<td>Walk</td>
<td>32 (46)</td>
</tr>
<tr>
<td>Leisure</td>
<td>13 (19)</td>
</tr>
<tr>
<td>Domestic</td>
<td>11 (16)</td>
</tr>
<tr>
<td>Work</td>
<td>12 (17)</td>
</tr>
<tr>
<td>Personal care</td>
<td>2 (3)</td>
</tr>
<tr>
<td>Total</td>
<td>70</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>TABLE 2</th>
<th>Targets chosen to be maintained or regained: working-age population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Target type</td>
<td>Maintain, n (%)</td>
</tr>
<tr>
<td>Walk</td>
<td>11 (37)</td>
</tr>
<tr>
<td>Leisure</td>
<td>2 (7)</td>
</tr>
<tr>
<td>Domestic</td>
<td>4 (13)</td>
</tr>
<tr>
<td>Work</td>
<td>12 (40)</td>
</tr>
<tr>
<td>Personal care</td>
<td>1 (3)</td>
</tr>
<tr>
<td>Total</td>
<td>30</td>
</tr>
</tbody>
</table>
Differences in target chosen by men and women were also apparent and are shown in Table 3. Work was similar in the two, but women were more likely to choose a domestic activity and men more likely to choose a leisure activity (P < 0.01). Negotiation added ~1 min to the consultation.

**Discussion**

The concept of treatment to target comes from hypertension, lipids and diabetes, where setting a target for levels and then trying hard to achieve it results in better health outcomes [7]. These conditions have the great advantage that they have objective outcome measures that are good surrogates for better health status. This is more difficult in RA as the outcome measures such as the 28-joint DAS (DAS-28) have subjective components, and defining adequate control, such as remission, requires further study and definition of the properties of the score. Treatment to target for RA has been studied at a European level with review of the literature [8] and expert recommendation [9].

The NICE guidance for RA discusses patient involvement in shared decision making with patients [2]. Shared decision making has been around for many years and is regarded as an important development [10]. However, the complexity of the negotiation and the educational needs of the patients to allow them to participate have been recognized [11]. This presumably led NRAS to write their document ‘know your DAS’ aimed at educating patients about the DAS [5]. This is a practical description of how the DAS is measured and used. It is clear from this study that this has not had a noticeable effect on the routine patients although it may have in NRAS members. Conveying the complexities of the dynamics of the DAS to patients may well be problematic and the scientific knowledge to underpin the education will often not be present. There is also the difficulty of negotiating a target with a patient with severe foot pain using a 28 joint count that does not include the feet.

Symptoms are, by definition, what patients complain of and so needed to be considered as a possible patient-derived target for treatment. Minimization of symptoms is an aim of treatment in any chronic disease. In RA, these would particularly be pain, stiffness and fatigue. However, translating these into a target is more difficult. All are subjective and as adverse symptoms most patients would like to be free of them. Deciding on how much pain would be difficult. This is compounded by the method of assessment, which is likely to be a visual analogue scale. This would put it entirely within the patients’ gift to either hit or miss the target and would therefore only have the function of deciding if the patient was happy with their condition. This is not in the nature of a target although it is probably how we have functioned for many years.

Previous research seeking patient views on outcomes identified pain and mobility as the major areas [12]. The problems of measuring pain were recognized by our participants. This leaves mobility, which is an activity and expressed as walking was the default choice of participants in this study.

Restricted activities did then appear to be the practical way to negotiate targets with the patient as suggested by our qualitative study [3]. It fits with judging impact according to what a condition stops someone doing and it proved easy for participants to understand and choose an activity with only one exception. The process may be refined by phrasing the question slightly differently.

For a stable patient: ‘What activity can you suggest, that if you were no longer able to do it, would indicate to you and us that you needed more treatment?’ For an unstable patient where treatment is being increased: ‘What activity are you hoping to regain as a result of this increased treatment that will indicate that the change has been a success and that you don’t require further increase in treatment?’

On reflection, rheumatologists have probably been functioning in a similar but less explicit way for many years. The decision to increase treatment being a balance between expected benefits and possible side effects interpreted through the patient. That is, you currently have these symptoms and loss of function. If we were to increase your treatment I would recommend this drug or change of dose. If it worked well, I would expect this improvement. These are the common side effects and monitoring requirements. Do you want it? Making this negotiation more explicit and setting the improvement in terms of a restricted activity against which it may later be judged, may have advantages in terms of measuring it and documenting patient involvement.

As you get nearer to the target, the potential benefits will become less and the toxicity of the drugs may increase as you get to lower choices of drug. The balance may change such that you choose not to go on with more aggressive therapy to hit your target. This probably means that a target will need to be identified for each therapeutic change. Similarly, over time, patient priorities and circumstances will change, necessitating renegotiation of targets. The frequency of this is yet to be determined.

What patients chose as targets was interesting. The default activity was walking, specified as a distance. This fits with medical histories and assessments for things such as the Disability Living Allowance (DLA) [13] and is relatively simple. It is interesting that those wishing to regain an

**Table 3** Targets chosen by males and females

<table>
<thead>
<tr>
<th>Target type</th>
<th>Male, n (%)</th>
<th>Female, n (%)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Walk</td>
<td>11 (39)</td>
<td>37 (54)</td>
<td></td>
</tr>
<tr>
<td>Leisure</td>
<td>10 (36)</td>
<td>7 (10)</td>
<td>&lt; 0.01</td>
</tr>
<tr>
<td>Domestic</td>
<td>2 (7)</td>
<td>14 (21)</td>
<td></td>
</tr>
<tr>
<td>Work</td>
<td>5 (18)</td>
<td>8 (12)</td>
<td></td>
</tr>
<tr>
<td>Personal care</td>
<td></td>
<td>2 (3)</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>28</td>
<td>68</td>
<td></td>
</tr>
</tbody>
</table>
activity were even more likely to express it as walking, whereas maintaining activity was more likely to be expressed in the more complex work, leisure or domestic activity.

The sex differences were also interesting in that the males were more likely to specify a leisure activity, whereas the females would specify a domestic activity. This presumably reflects sex differences in perceived social roles. It is interesting that the target of work was similar in both.

Maintaining occupation did prove to be a common target for those in employment. Hanging on to a job was seen as important. It is interesting that regaining work was not a target. The only participant expressing her target as increased work was already working and wished to increase her hours. This suggests that once the job is lost and the patient has adapted to that loss, the motivation to work is lost. This has profound implications for the maintenance of employment in patients with RA where there is a significant risk of unemployment at 5 years [14] and even significant loss in the pre-diagnosis phase [15].

It suggests that preventing the loss of the job in the first place is crucial and that getting people to return to work later will be much more difficult. Anecdotally, we have seen patients who have responded very well to trial drugs several years after stopping work, such that they could function at their old jobs, but they have other priorities by then.

A weakness of this project is that it reflects one consultant negotiating with usually longstanding patients. It is not possible to know if other consultants would negotiate in a similar way with similar results. It is possible that patients were led into their targets, although all attempts were made to avoid this. The project needs to be repeated by different people in other settings to judge how representative it is.

In summary, this project shows that it is possible to negotiate a target for treatment with a patient, expressed as an activity to be maintained or regained, in a busy NHS clinic. Maintaining work is a common target for those in employment, but regaining work once it is lost is not a target. This suggests that it is more practical to keep people in work rather than try and get them back to work once the work habit is lost. Further studies will be necessary to assess the usefulness of this negotiation.

Disclosure statement: The authors have declared no conflicts of interest.

References

Rheumatology key messages

- Patient-derived targets for RA treatment are expressed as restricted activities.
- Stable RA patients wish to maintain activities, whereas unstable patients wish to regain them.
- Work ceases to be an RA patient’s target once it is lost.

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