

Implementing a patient-initiated clinic for people with rheumatoid arthritis: a qualitative evaluation.

Victoria Goodwin¹, Sue Child¹, Mark Perry², Christian Gericke³, Richard Byng¹

¹NIHR CLAHRC for the South West Peninsula

²Plymouth Hospitals NHS Trust, ³The Wesley Research Institute, Brisbane, Australia

Background

Rheumatoid Arthritis (RA) is a long term condition causing unpredictable episodes of pain and disability. Management of RA in secondary care is traditionally undertaken by regular clinician-driven reviews. These are often when the patient is well. Conversely if the patient experiences a disease flare-up they may be unable to see a specialist for many months. This results in a mismatch between clinical need and input.

Based on previous research findings, a patient-initiated review system called Direct Access (DA) was implemented for people with RA by Plymouth Hospitals NHS Trust. This involved an education session for patients about the new system, a telephone helpline and access to a specialist review within 10 working days.

Aim

To explore the experiences of patients and staff of a DA system to understand the process of implementation.

Methods

- Observation of patient education sessions
- Semi-structured interviews with patients (n=23) and staff (n=7)
- Thematic analysis identified four key themes.

Staff

“the feedback I’ve had has been mainly extremely positive and in most cases they are delighted with the service…”

Building patient confidence

“..a great concept for patients who have stable rheumatoid who’ve got a specific disease related problem are able to ring up and get an appointment sorted out very quickly...I think that works really, really well and that’s what it’s designed for”

Right place, right time

“...I’ve had some who have admitted their disease has got worse but have done nothing about it and some of these patients now I feel shouldn’t have gone into DA.”

Safety

“I’m getting more direct access patients and they come with more active, complex problems perhaps more than one problem. I am realising that a 15 minute routine follow-up slot perhaps isn’t long enough to address all the issues.”

The everyday challenges of managing change

Patients

“I trust [the nurse], I’ve known her a long, long time and I trust her implicitly.”

“..I’ve got to catch 2 buses which takes about an hour and a half to see a consultant for about 5 minutes, which in my estimation, is a complete waste of time unless something is wrong with me.”

“I don’t say it’s good for everyone because some people do get very confused you know about different things.”

“..I was a bit nervous really thinking oh if I’m not going to get to see somebody regularly...”

Conclusions:

Direct Access for people with RA:

- Increases patient autonomy and is a more person-centred approach
- Is not appropriate for everyone
- May be a suitable system for the secondary care follow-up of people with other long term conditions.