

NRAS

Changing Minds, Changing Services, Changing Lives for People with RA and AJIA

- **Support** everyone living with the impact of RA or AJIA at the start and every step of their journey
- **Inform** – be their first choice for reliable information,
- **Empower** all to have a voice and take control of their RA or AJIA



A Survey of Psychological Support Provision for People with Inflammatory Arthritis in Secondary Care in England 2014

- *Overall, 73% rated their unit's psychological support provision as 'inadequate'*
- *4% rated it as 'good'. A small number of units believed that psychological support did not fall within their remit (12%)*
- *8% had a psychologist in the team*
- *Most units (68%) did not routinely screen patients to identify psychological difficulties.*

The Authors. *Musculoskeletal Care* published by John Wiley & Sons Ltd.



A UK Survey of adults with RA and JIA on the impact of their disease on mental health

Aims and Objectives

1. Assessment of psychological need in adults with RA or AJIA in UK
2. Determine the proportion of RA & JIA adults in the UK who have requested, been offered and received psychological support and how these relate to levels of psychological well-being
3. Establish full range of barriers and facilitators to seeking emotional and psychological support
4. Determine the psychological support needs of adults with RA & JIA in the UK
5. Understand how rheumatology services, third sector and government can improve psychological support needed for people with RA & JIA



Participant profiles

- 1999 respondents (of which 1650 used as final sample) - 97% RA, 3% AJIA
- 88% female, average RA age 57, AJIA age 39, 93% white British
- 72% RA & 66% AJIA were married living with partner, 22% RA & 15% AJIA living alone, 6% of RA and 20% AJIA with friends, relatives, supported living
- 13% diagnosed with RA within 2 years
- Average disease duration 12 years for those with RA and 32 years for AJIA.



Results

- People with RA and adult JIA are much less satisfied with life, believe the things in their life are less worthwhile, and are less happy.
- On average RA respondents were living with an additional 2 comorbidities
- 1 in 3 people who had asked for or were offered psychological support had never received it.
- The proportion of people scoring poorly on life satisfaction and life worth was over 7 times greater in those with RA and adult JIA.



- 50% of those with clinical anxiety and 69% of people with clinical depression have not been formally diagnosed with a mental health condition, despite meeting the criteria.
- 50% of respondents with RA and 1 in 3 with AJIA who had clinical levels or a formal diagnosis of depression or anxiety had not received psychological support.
- In a majority of cases, people wanted support face-to-face with a professional when they felt it was needed.
- 2 in 5 people have never been asked by their health professional about their emotional/psychological health.

Reported barriers to accessing psychological support

- People not knowing what support is available.
- Overall lack of optimism about their future
- Feeling their distress was not severe enough to need help
- Difficulty in asking for help with emotions
- Health professionals not having enough time to help them with emotions.
- Difficulty in talking about emotions
- Health professionals never or rarely asking about emotions.
- Health professionals preferring to focus on physical health.
- Preferring to manage emotions themselves



Recommendations

- Mental health assessments should be integrated into RA treatment journey from diagnosis and then periodically (e.g. at annual review).
- Patients need to know how to ask for and access psychological support.
- The entire MDT needs to know how their services can support the mental health of their patients.
- Need to upskill HCPs to offer psychological interventions, e.g. CBT
- Sign-posting to third sector organisations (such as NRAS) can ensure alternative support is available.
- Rheumatology teams need appropriate funding and resource.
- Further research needed into the reasons behind some of these findings.



The Challenge

- Meeting the need
- Integrating mental health assessment and monitoring within RA treatment journey
- Culture shift from physical to whole person treatment
- Developing innovative models of delivery
- System response to treatment of comorbidities
- Increased self management empowering the patient to self direct care.



Thank You

The Good Physician treats the disease, the great physician
treats the person who has the disease

Sir William Osler

1849-1919

Please take a copy of the report with you

Iain McNicol
Head of RA Services

