

# **Osteoporosis, falls and fractures in chronic inflammatory rheumatic disease**

## **Lay Summary**

### **Overview**

This generous scholarship from Arthritis Australia provided funds for me to undertake my second year of studies for my PhD. Osteoporosis, fractures and falls are an important cause of morbidity and mortality within the general population. Patients with chronic inflammatory rheumatic diseases (CIRDs), including rheumatoid arthritis (RA), psoriatic arthritis (PsA), systemic lupus erythematosus (SLE) and ankylosing spondylitis (AS) are at higher risk of osteoporosis, falls and related fractures. Our research is aimed at understanding the experience of clinicians and patients in the management of osteoporosis, falls and fractures and better defining the burden of disease in these high-risk patients in Australia.

### **What problems did you try to solve, or gaps in knowledge did you try to fill? What did you discover during the course of the grant?**

To understand the existing perspectives of clinicians in the diagnosis, management and prevention of osteoporosis, falls and fractures we conducted a systematic review of primary qualitative studies. There were 27 studies, with 1662 participants (including two mixed-methods studies with open-ended questionnaires) with 521 participants from studies utilising semi-structured interviews and focus groups. The participants included various types of clinicians, with physicians (primary care, specialists), surgeons, allied health professionals, pharmacists and nurses, who reported low priority with unclear health significance, challenges with collaboration and lack of clinical confidence as barriers to provision of care. Despite barriers, clinicians acknowledged their role in promoting healthy ageing and voiced the desire for educational opportunities and increased public health awareness.

A primary qualitative study with interviews or focus groups was conducted with 25 patients with CIRDs and osteoporosis on their experience in management of their bone health. We found patients were ambivalent about osteoporosis, falls and fractures, whilst paradoxically disappointed with deteriorating health and changing sense of self. They described frustration with generic management approaches without consideration of their underlying rheumatic disease, poor accessibility to treatment and exhaustion by the increasing burden of healthcare. However, patients with CIRDs took pride in health ownership by embracing autonomy, information seeking and building community while entrusting care in clinicians whom they trust.

Complementing this, we are currently undertaking a primary qualitative study with GPs and rheumatologists in their experience in osteoporosis, falls and fractures in patients with CIRDs. 12 (7 GPs, 5 rheumatologists) interviews have been conducted

thus far, with emerging themes including the complexity of CIRDs obscuring preventive care, variability in clinical confidence with GPS reporting comfort in delegating to specialist care, building trusting longitudinal therapeutic relationships and disappointment with suboptimal care delivery with constrained resources. We plan to conduct an additional 10-20 interviews with GPs and rheumatologists from broad backgrounds to enable further development of comprehensive and rich themes.

A scoping review was performed to describe the currently available literature on the epidemiology and risk factors associated with osteoporosis, falls and fractures in CIRDs. While there were 279 studies identified, most studies were in RA, in single-centre cohorts using cross-sectional data. There was limited research available on osteoporosis, falls and fractures in other CIRDs, most notably in falls. Additionally, despite widespread use of biologic and targeted synthetic disease-modifying anti-rheumatic drugs (bDMARDs and tsDMARDs) since 2000, there are limited studies exploring the impact of these medications on osteoporosis, falls and fractures. Notably there were only 5 studies from Australia and New Zealand. This highlighted the need for future research using prospectively collected longitudinal data in CIRDs, inclusive of non-RA conditions. Thus, we are currently undertaking a study utilising data obtained from the Australian Longitudinal Study of Women's Health (ALSWH), which includes linked data from Medicare, the Pharmaceutical Benefits Scheme (PBS), hospital admissions and emergency department presentations to explore the epidemiology of osteoporosis, fractures and falls in CIRDs and relevant risk factors.

Are you planning to continue the research?

Yes. We hope to utilise the findings of the above studies to design a multi-faceted intervention addressing barriers and incorporating ideas obtained from primary qualitative studies which is acceptable to key stakeholders including rheumatologists, GPs and consumers.

## **Scientific summary**

### **What were the main scientific objectives of the grant?**

The main objectives of my PhD are as follows:

1. To understand the perspectives and experiences of the management and prevention of osteoporosis, falls and fractures in patients with CIRDs from the perspective of rheumatologists, GPs and patients.
2. To determine the epidemiology of and risk factors for osteoporosis, falls and fractures in patients with CIRDs in Australia.

### **What were the main scientific achievements of the grant?**

The five studies to form my PhD are as follows:

1. Perspectives of health-care providers on osteoporosis, falls and fracture risk:  
A systematic review and thematic synthesis of qualitative studies – complete, published in medical journal.

A thematic synthesis was performed on articles identified through four databases, inclusive of 27 studies, with 1662 health-care providers including general practitioners (GPs), physicians, surgeons, allied health professionals, nurses and pharmacists. This number included two mixed-methods studies, which included questionnaires with open ended questions. There were 521 participants from studies utilising semi-structured interviews and focus groups. Only studies available in English were included. Studies were assessed using the modified Consolidated Criteria for Reporting Qualitative Health Research (COREQ) framework. Data was analysed using inductive thematic analysis, using a qualitative description approach. All articles were read line-by-line and text coded into inductively derived concepts, grouped into themes and subthemes and discussed within the research team then defined in an iterative process to ensure researcher triangulation.

There was identification of six themes: overshadowed as a disease entity, uncertainty in decision making, frustration with interdisciplinary and systemic tension, avoiding medical paternalism, desire for improved care and embracing the responsibility. Our study highlights the HCPs' complex and varied perspectives contributing to the significant gap between the public health necessity that is osteoporotic fracture prevention. Optimal care is hampered by inadequate priority with lack of perceived connection with illness or morbidity by HCPs, deficiencies in interprofessional collaboration and gaps in knowledge. The contextual background of low public health awareness, antagonistic views towards ageing and the ageing process and deficits in resourcing further hinder care. However, HCPs expressed desire for improved care and improving expertise. These findings support the implementation of locally relevant, multifaceted, patient-focussed, patient and provider acceptable strategies combining education, healthcare re-structuring and shared decision making to bridge the osteoporosis care gap.

2. Primary qualitative study utilising focus groups and interviews with patients with CIRD and osteoporosis to understand their experiences in the management of osteoporosis, falls and fractures – complete, manuscript in preparation for submission to journal.

A qualitative study utilising interviews and focus groups was conducted with 25 patients with various CIRDs, including rheumatoid arthritis (17), systemic lupus erythematosus (3), ankylosing spondylitis (1) and psoriatic arthritis (2) diagnosed by a rheumatologist and concurrent osteoporosis, as defined by the WHO-definition. Participants were purposively sampled from two metropolitan tertiary teaching hospitals in NSW. Participants who were <50 years of age or unable to speak sufficient English to participate or provide informed consent were excluded. Interviews and focus groups were transcribed, with transcripts read line-by-line with coding performed using the grounded theory methodology. Concepts identified relating to experiences of osteoporosis, falls and fractures were identified using an inductive approach, with related concepts organised into themes and subthemes discussed by investigators until consensus reached.

Most participants were women (17, 68%) with an average age of 72 years. We found many patients were ambivalent to the diagnosis of osteoporosis, particularly to falls, with a sense of 'inevitability' given CIRD diagnosis and treatments. Paradoxically, patients, particularly those who had sustained a previous fracture, reported a disappointing sense of frailty, loss of independence and sense of self, with some living with heightened anxiety. Treatment was perceived as burdensome and frustrating, particularly physical exercise recommendations which were limited by symptoms related to rheumatic disease but the experience of living with chronic disease provided empowerment in self-advocacy, education seeking, fostering positive trusting relationships with treating clinicians and building community. This highlights the complexity of the lived experience of patients living with CIRD and the need for multidisciplinary collaborative and accessible care delivering individualised healthcare.

3. Primary qualitative study with GPs and rheumatologists in their experience in managing patients with CIRD with regards to osteoporosis, falls and fractures – continuing data collection and analysis.

A primary qualitative study with GPs and rheumatologists, and trainees within accredited programs, on the perspectives and experiences in osteoporotic fracture prevention and management in CIRDs is currently being undertaken. Interviews have been conducted with 12 clinicians thus far (7 GPs, 5 rheumatologists) from different settings (private and public, metropolitan and non-metropolitan). Emerging themes including the complexity of CIRDs obscuring preventive care, variability in

clinical confidence with GPs reporting comfort in delegating to specialist care, building trusting longitudinal therapeutic relationships and disappointment with suboptimal care delivery with constrained resources. We plan to conduct an additional 10-20 interviews with GPs and rheumatologists from broad backgrounds to enable further development of comprehensive and rich themes.

4. Scoping review on studies conducted on the epidemiology and risk factors for osteoporosis, falls and fractures in CIRD – complete, submitted to medical journal.

A scoping review was conducted to describe the available literature on the epidemiology and risk factors for osteoporosis, falls and fractures in four CIRDs, RA, PsA, AS and SLE. This scoping review used the Joanna Briggs Institute (JBI) framework for scoping reviews with a comprehensive search performed of three databases. Observational studies from the year 2000 reporting on the epidemiology and/or associated factors for osteoporosis, falls and fractures in RA, PsA, AS or SLE were included. There were 279 studies which met inclusion criteria; 163 in RA, 19 in PsA, 48 in AS and 59 in SLE, 57.3% of which were cross-sectional studies. The greatest output of research from Europe (39.1%) and Asia (29.7%). Notably there were only 5 studies from Australia or New Zealand. Most papers reported on osteoporosis and fractures as outcomes, with only 26 reporting falls, of which 23 were in RA (inclusive of 12 small single centre cross-sectional studies). Demographic, disease-related parameters and medications, particularly glucocorticoids, are the most frequently explored risk factors.

In summary, observational data available on the epidemiology and risk factors for osteoporosis and fractures are from mostly cross-sectional studies, based on populations from Europe, UK, East Asia and the USA. Most available literature is in RA and SLE. Demographic factors, measures of disease activity and medications, particularly glucocorticoids, are the most frequently explored risk factors. Falls research is limited in CIRD, largely to cross-sectional studies in RA, despite falls carrying the significant burden of healthcare cost, individual morbidity and mortality. Future research should utilise large, prospective cohorts of CIRD patients, inclusive of patients from low-middle income countries, with inclusion of falls data. Specifically, there is limited Australian research in this area, thus, future research with large Australian cohorts may enable better understanding of the risk of osteoporotic fractures and falls in Australian CIRD patients which may enable development of interventions within our unique healthcare system.

5. The epidemiology and risk factors for osteoporosis, falls and fractures in Australian women with inflammatory arthritis – currently undertaking statistical analysis.

From our scoping review, we found limited Australian data on the epidemiology and risk factors for osteoporosis, falls and fractures in CIRD. The Australian Longitudinal Study on Women's Health (ALSWH) is a large database which has collected information on women of three age cohorts (younger, aged 18-23; mid-age 45-50; older 70-75) at inception in 1996. Data has been collected through surveys, on healthcare outcomes and well-being over 20 years. Using data from the ALSWH study, we aim to explore 1) The epidemiology of osteoporosis, falls and fractures in women with RA or other inflammatory arthritis, compared to those without; 2) To examine the risk factors for osteoporosis, falls and fractures in individuals with RA or "other inflammatory arthritis," compared to those without and the evolution of risk factors over time that may predict future fractures and falls; 3) The screening gap for osteoporosis in patients with RA or "other inflammatory arthritis," and 4) The treatment gap. Musculoskeletal diagnoses, including RA, are based on self-report in the ALSWH. To validate diagnoses, linked pharmaceutical data from the Pharmaceutical Benefits Scheme) and International Statistical Classification on Disease and Related Health Problems (ICD-10) codes from hospital admissions will be used to validate a cohort of women who have a diagnosis of RA or "other inflammatory arthritis." Additional linked data from the Department of Human Services (Medicare), Emergency Department presentations, hospital admissions and the PBS will be obtained for analysis.

On preliminary review of ALSWH data, 609 women in the older (1921-1926), 119 in the middle (1946-1951) and 141 in the young (1973-1978) cohort self-report a diagnosis of RA. On cross-sectional analysis of each survey in which osteoporosis, falls and fracture were listed as a question, a greater proportion of those who self-report RA had reported a falls, injurious falls and fractures in the previous 12 months. We plan to further validate the RA cohort utilising linked data and assess the epidemiology and risk factors for ED presentations and hospital admissions with falls and/or fractures and Medicare/PBS data for DEXA and prescriptions for osteoporosis pharmacotherapy to identify the screening and treatment gap.

What problems, if any, did you encounter in achieving the project's objectives and how did you address them?

The main challenge encountered was the administrative work and time required to access linked data, including Medicare, PBS, Emergency Department presentations and hospital admission data. This has delayed the quantitative study on the epidemiology of osteoporosis, falls and fractures in patients with CIRD utilising ALSWH datasets. The university has provided support in navigating these challenges and analysis of linked data is currently underway and is expected to be complete in late 2025.

What is the plan for dissemination of findings?

The systematic review on primary qualitative studies has been published in Archives of Osteoporosis in 2024<sup>1</sup>. The results were also presented at the Asia-Pacific League Against Rheumatism (APLAR) Annual Scientific Meeting in Singapore in August 2024. The scoping review has been submitted for publication to BMJ Open. The primary qualitative study with patients is completed, with a draft manuscript currently being prepared for submission to a medical journal. We intend to submit all studies for publication and disseminate our findings at national and international conferences.

1. Cho C, Bak G, Sumpton D, Richards B, Sherrington C. Perspectives of healthcare providers on osteoporosis, falls and fracture risk: a systematic review and thematic synthesis of qualitative studies. Archives of Osteoporosis. 2024 Sep 24;19(1):90.