RMD Open
Rheumatic & Musculoskeletal Diseases

VIEWPOINT

Getting prepared for the silver wave: challenges in conducting rheumatic and musculoskeletal disease research in older adults

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To cite: Truijen S, Austen S, Magdelijns F, *et al*. Getting prepared for the silver wave: challenges in conducting rheumatic and musculoskeletal disease research in older adults. *RMD Open* 2025;**11**:e005280. doi:10.1136/rmdopen-2024-005280

Received 20 November 2024
Accepted 11 February 2025

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ABSTRACT

Research in older adults diagnosed with rheumatic and musculoskeletal diseases (RMDs) comes with unique challenges, as these patients often face consequences of ageing, such as multimorbidity, polypharmacy, and geriatric syndromes (eg, frailty). In this viewpoint, we highlight various clinical, ethical, regulatory and logistical challenges, including, among others, issues with the decision-making capacity of older adults regarding study participation. We emphasise the need for feasible strategies and protocols to enhance research inclusivity in order to ultimately improve evidence-based care for the growing population of older adults with RMDs.

Older adults, commonly defined as those aged 65 or older, are vastly underrepresented in clinical research across almost all medical fields.[1] In rheumatic and musculoskeletal (RMD) research, this is particularly concerning, as many RMDs are especially prevalent in the senior population. Underrepresentation of older adults with RMDs in translational and clinical studies ultimately results in significant knowledge gaps in clinical care and thus in management recommendations.[2–5]

Ignoring older adults is no longer sustainable. Currently, about one in five people in the European Union is aged 65 or older, and projections suggest that by 2050, nearly one-third of the population will consist of older adults.[2 6] This demographic shift requires us to rethink the design of translational and clinical studies so that we, as rheumatology professionals, are prepared to address the specific needs of older adults.[6]

CHALLENGES IN CARE FOR OLDER ADULTS

Rheumatology professionals will increasingly be faced with the challenges associated with ageing, such as altered pain perception, altered immunity and changes in pharmacokinetics. This parallels an increase in 'consequences of ageing,' such as multimorbidity, polypharmacy and geriatric syndromes (eg, sarcopenia, delirium or frailty).[2] The consequences of ageing necessitate careful consideration and adaptation of treatment strategies for individual patients. The optimal timing and approach for implementing geriatric management strategies, such as referral for a Comprehensive Geriatric Assessment, in older patients with RMDs remain, however, unclear.[2]

As rheumatology professionals, we may not fully recognise that the prevalence of geriatric conditions is expected to increase significantly over the next few years.[7] For example, between 2019 and 2050, the global prevalence of dementia across all age groups is projected to rise by 117% (95% CI 100% to 133%) primarily due to population ageing. The total number of dementia cases is anticipated to increase even more, by 166% (95% CI 148% to 185%), driven by a combination of population ageing and overall population growth.[7] The global prevalence of mild cognitive impairment, the preclinical and transitional stage between healthy ageing and dementia, is currently 15.6% (95% CI 13.2% to 18.0%) among community-dwelling adults aged 50 years and older.[8] Although these data may initially seem less relevant for rheumatology professionals, it is important to realise that the significant increase in older adults with dementia will likely lead to more frequent consultations for advice on diagnosis and management regarding RMDs in this group. In addition, there is a higher risk of mild cognitive impairment and dementia among individuals with RMDs. This risk is partly attributable to chronic inflammation, as seen in conditions like rheumatoid arthritis (RA), through mechanisms such as 'inflammageing'.[9]

In the Netherlands, inclusion of participants with dementia in studies that fall under the Medical Research Involving Human Subjects Act is prohibited by law if the research can also be conducted in participants without dementia. In the context of RMDs, an area of uncertainty in adults with dementia involves how neuropathological changes alter the perception and expression of joint pain and stiffness. As a result, important knowledge gaps may persist, simply because this population is not being studied.

The consequences of ageing are even more pronounced in nursing home residents—a population often facing very severe multimorbidity including dementia, higher levels of frailty and high levels of dependency across multiple domains. There is considerable uncertainty regarding the prevalence and impact of RMDs among nursing home residents. A recent systematic review by our group showed that the prevalence of musculoskeletal pain among this population ranged from 0.9% to 77%, while the prevalence of specific RMDs, such as RA, gout and osteoarthritis, ranged from 0.6% to 67.5%.[10] Inaccurate recognition and challenges in diagnosis of RMDs in nursing home residents likely contribute to this large heterogeneity in prevalence rates. Especially older adults present with a 'typically atypical' disease profile. For example, Parkinson's disease and sarcopenia may mask symptoms of polymyalgia rheumatica.[2] Consequently, these patients may not receive adequate pain medication or antirheumatic treatment.[11]

In short, the increasing worldwide prevalence of geriatric syndromes, combined with restrictive regulations that hinder participation for older adults with dementia, underscores the need for a more inclusive research strategy in the RMD field. Gaining more knowledge in this area can ultimately lead to better-tailored care for older patients. Similar to transition clinics for adolescents moving from paediatric to adult care, older adults experiencing consequences of ageing also have unique needs that may require specialised care.

CHALLENGES IN RESEARCH STUDIES IN OLDER ADULTS

To answer knowledge gaps on management of older adults with RMDs, a first step is to improve participation of older persons in research. Over the last few years, we initiated several studies to compare the consequences of ageing between patients with RA and population controls and to understand the burden of RMDs in nursing homes. The 5Ts framework (Target population, Team, Tools, Time and Tips to accommodate) can serve as a practical guide to include older adults in research projects (table 1).[12] As an example, in line with the 5T 'Time', we carefully considered how to balance between data collection and participant burden by ensuring that we collected only what was essential to answer the underlying research question. Despite considering the 5Ts in the design of our studies, we still encountered several challenges (table 1) during the execution of our projects. We would like to highlight a few of these challenges. Knowing about these challenges beforehand could be valuable for other researchers when planning similar studies.

Approval from the medical ethics committee

When seeking approval from the medical ethics committee (MEC), numerous barriers were encountered for conducting research in nursing home residents, both with and without dementia. Although the MEC follows legal guidelines concerning the inclusion of participants with dementia, there appeared to be limited awareness of the distinct differences between nursing home residents with and without dementia, particularly regarding pain perception and symptom presentation. It is crucial to raise awareness within the MEC that conducting research in older adults with RMDs and dementia is particularly important, as knowledge about this group is very limited. Also, the physical examination of the musculoskeletal system was initially viewed by the MEC as too burdensome for nursing home residents with dementia, and therefore, deemed unnecessary for this group. We had to clarify that a standard physical examination is routinely performed in the daily care of nursing home residents. Paradoxically, the physical examination of the musculoskeletal system often turned out to be less burdensome for nursing home residents with dementia than for those without, as the latter group typically resided in nursing homes due to severe chronic somatic diseases and needed complex, ongoing care in multiple domains. Complex multimorbidity made undressing for a physical exam or turning in bed significantly more burdensome for these participants.

Informed consent

When preparing our studies, we carefully considered approaches to obtain informed consent from older adults with visual and auditory impairments (eg, using large print for subject information sheets). For nursing home residents with dementia, informed consent had to be provided by their legal representative. However, we did not anticipate that many older adults without dementia had conditions like hemiparesis or severe Parkinson's disease, or were illiterate, which made the informed consent process challenging. We addressed this by stating in the research protocol that the researcher was allowed to fill in the participant's name and date of birth on the informed consent form. After this, the participant could sign, even with an 'unconventional' signature.

Moreover, older adults may also have mild cognitive impairment or beginning dementia that is not immediately apparent, as there is no or little interference with their daily activities until more complex tasks are required. Signs of cognitive decline, therefore, only became evident when explaining the study or reviewing the subject information sheet together with the older

Table 1 Challenges, suggested solutions and recommendations in alignment with the 5Ts framework for research projects involving older adults with and without dementia[12]

5T category	Examples of challenges	Suggested solutions and recommendations
Target population	Older adults are often excluded from studies which limits generalisability to the globally ageing population.	Avoid exclusion criteria such as presence of multimorbidity (including (mild) cognitive impairment) and geriatric syndromes.
	Lack of interest to participate due to ‘ageism’; older adults feel ‘too old’ to participate in research.	Address age-related biases.
Team	Older adults often rely on informal caregivers for appointment scheduling or adhering to a study protocol.	Engage both participants and their informal caregivers as members of the research team.
	MEC overestimated the burden of participating in research for older adults with dementia.	Raise awareness within the MEC, by explaining the significant knowledge gaps in this population. Make clear that routine exams and assessments are common in daily nursing home care.
Tools	Recruitment of older adults with multimorbidity and geriatric syndromes in research projects is challenging.	Use recruitment strategies appropriate to the target population, for example, asking medical staff or informal caregivers.
	Older adults may refrain from participating when the research process (signing ICF, contact with researcher, questionnaires) is online.	Although more time-consuming, send the ICF via post, contact participants by telephone, send paper questionnaires.
Time	Collecting data usually takes more time in older participants; more measurements heighten participant burden.	Balance data collection and participant burden; only collect data essential to the research question.
	Appointments were often rescheduled due to intercurrent health issues.	If possible, collect data at the participants’ (nursing) home.
Tips to accommodate	Mild cognitive impairment or beginning dementia is not immediately apparent.	Develop a protocol to evaluate decision-making ability. A legal representative could provide an extra safety measure around the ICF procedure.
	Visual, auditory, cognitive and literacy challenges in older adults with conditions such as cerebrovascular and Parkinson’s disease.	Describe tailored approaches in research protocol, for example, using large print for subject information sheets, language aids, permitting researchers to prefill details such as the participant’s name and date of birth on the ICF.

ICF, informed consent form; MEC, medical ethics committee.

adult. In cases where the cognitive abilities of a potential study participant are questioned, it is crucial to assess whether the participant is actually capable of giving informed consent. It is important to establish in advance how to handle these situations. This may include developing protocols for assessing decision-making capacity, particularly when cognitive decline is not noted in the medical record of an older adult. In such cases, involving a legal representative could provide an extra safety measure around the informed consent process.

Of note, older adults with aphasia were often underestimated with regard to their decision-making capacity by researchers, but with the help of language aids, they could clearly indicate their willingness to participate.

Logistic and health-related barriers to study participation

For frail older adults, the need to travel to the study site was frequently an important barrier for study inclusion, as they rely often on their informal caregiver for transportation. Due to intercurrent health issues (eg, flare RA or emergency surgery), appointments often needed to be cancelled or rescheduled. By combining the visit to the outpatient clinic with a study visit, we were still able to collect data in this group.

Ageism

Strikingly, when informing older adults about the study, we frequently heard that they did not want to participate because they felt they were ‘too old’. This reflects ageism against themselves and likely their peers.[13] We were surprised that older adults expressed these thoughts, as they viewed themselves as ‘redundant’ in society, and this impacted how they viewed their ability to contribute to research. Providing additional information about the study and addressing age-related biases often helped to increase willingness to participate.

Last, we want to emphasise that despite the challenges, we also encountered many positive outcomes. We found a high level of willingness to participate, especially in nursing homes, where residents, family members and staff all recognised the importance of research in this specific population. Many older adults made significant efforts to participate in the study. They also expressed appreciation, noting how pleased they were with the extra attention given to their specific challenges.

CONCLUSIONS

Conducting research in older adults with RMDs is highly needed but also presents a number of unique challenges. We need to resist the temptation to look away from the older patient group, simply because it is perceived as 'difficult', 'time-consuming' or 'low yield'. Instead, we should embrace the opportunity to make a meaningful difference, with the 5T framework serving as a valuable guide to promote research inclusivity, in order to enhance the outcomes of older adults with RMDs.

Contributors MvO contributed to the idea generation. All authors contributed equally to the writing, review and editing of this manuscript. MvO is guarantor for the manuscript. ChatGPT was used to improve the fluency of some sentences.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None declared.

Patient consent for publication Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

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REFERENCES

1 Forsat ND, Palmowski A, Palmowski Y, *et al*. Recruitment and Retention of Older People in Clinical Research: A Systematic Literature Review. *J Am Geriatr Soc* 2020;68:2955–63.
2 van Onna M, Boonen A. Challenges in the management of older patients with inflammatory rheumatic diseases. *Nat Rev Rheumatol* 2022;18:326–34.
3 Rothwell PM. External validity of randomised controlled trials: "to whom do the results of this trial apply?" *Lancet* 2005;365:82–93.
4 Buttgereit T, Palmowski A, Forsat N, *et al*. Barriers and potential solutions in the recruitment and retention of older patients in clinical trials-lessons learned from six large multicentre randomized controlled trials. *Age Ageing* 2021;50:1988–96.
5 Palmowski A, Buttgereit T, Palmowski Y, *et al*. Applicability of trials in rheumatoid arthritis and osteoarthritis: A systematic review and meta-analysis of trial populations showing adequate proportion of women, but underrepresentation of elderly people. *Semin Arthritis Rheum* 2019;48:983–9.
6 The Lancet Regional Health-Europe. Securing the future of Europe's ageing population by 2050. *Lancet Reg Health Eur* 2023;35:100807.
7 GBD 2019 Dementia Forecasting Collaborators. Estimation of the global prevalence of dementia in 2019 and forecasted prevalence in 2050: an analysis for the Global Burden of Disease Study 2019. *Lancet Public Health* 2019;7:e105–25.
8 Bai W, Chen P, Cai H, *et al*. Worldwide prevalence of mild cognitive impairment among community dwellers aged 50 years and older: a meta-analysis and systematic review of epidemiology studies. *Age Ageing* 2022;51:afac173.
9 Myasoedova E, Sattui SE, Lee J, *et al*. Cognitive impairment in individuals with rheumatic diseases: the role of systemic inflammation, immunomodulatory medications, and comorbidities. *Lancet Rheumatol* 2024;6:e871–80.
10 Austen S, Kamps I, Boonen AERCH, *et al*. Prevalence of rheumatic and musculoskeletal diseases (RMDs) in nursing home residents: a systematic literature review. *Eur Geriatr Med* 2024;15:1245–58.
11 Achterberg WP, Erdal A, Husebo BS, *et al*. Are Chronic Pain Patients with Dementia Being Undermedicated? *J Pain Res* 2021;14:431–9.
12 Bowling CB, Whitson HE, Johnson TM. The 5Ts: Preliminary Development of a Framework to Support Inclusion of Older Adults in Research. *J Am Geriatr Soc* 2019;67:342–6.
13 Misra D, Buehring B, Yung R, *et al*. Ageism and rheumatic diseases. *Lancet Rheumatol* 2024;6:e817–9.