Arthritis and disability

Executive Summary

Never Stand Still UNSW Arts & Social Sciences Social Policy Research Centre

Prepared for Arthritis Australia

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Executive summary

Arthritis Australia commissioned the Social Policy Research Centre (SPRC) at UNSW Australia to carry out research on the lived experience of people with arthritis related conditions. This report outlines the methods, findings and implications of the research.

Arthritis is the second leading cause of disability and the most common cause of chronic pain in Australia; it is the most prevalent long-term health condition, affecting 3 million people or about 15 per cent of the population. Studies are available on the health costs and loss of productivity associated with arthritis, but not as much is understood about the extent to which arthritis is associated with disability – who is affected, how people are affected, what helps people cope with their condition day to day, and how support services can be improved. Improving understanding of the disability impact of arthritis is particularly important given the transition in Australia to the National Disability Insurance Scheme and the impact this may have on service availability and delivery.

The research design involved mixed methods. A literature review focused on policy, programs, support and service models relevant to arthritis and disability in both Australian and international literature. A consumer roundtable and in-depth interviews with people with arthritis-related disability provided qualitative data. An online survey was conducted to provide quantitative and qualitative data to determine the extent to which the findings from the literature review, consumer roundtable, and interviews, were applicable to a broader population of people with arthritis in Australia.

A total of 819 people with arthritis volunteered to participate in this study through the consumer group (13), interviews (28), and the online survey (778). Participants were recruited through the membership networks of state and territory affiliates of Arthritis Australia, and other organisations including Lupus NSW, Carers Australia, Council on the Ageing, and Pain Australia. Participants in the interviews were people who self-identified as having disability resulting from their arthritis, and were selected to ensure representation across states and territories, women and men, people with arthritis and their carers, people with different types of arthritis, and people who had experienced arthritis for different lengths of time.

Participation in the group discussion and online survey was open to anyone with arthritis or caring for someone with arthritis, regardless of whether it caused disability.

Research participants were representative of the broader Australian population living with arthritis with respect to age distribution, with 64 per cent of participants aged less than 65 years. However, women (84 per cent of participants) and people with rheumatoid arthritis (35 per cent) were over-represented, while people identifying as Aboriginal or Torres Strait Islander or from a culturally and linguistically diverse community[1] were under represented. This is likely to reflect the membership base of the organisations through which participants were recruited.

The information provided by participants was analysed thematically against the rights in the *UN Convention on the Rights of Persons with Disabilities* in the areas of health, habilitation and rehabilitation, work and employment, standard of living and social protection, and family and social participation. In addition the Personal Wellbeing Index was used to measure participants' quality of life and compare it with that of the Australian population as a whole.

The breadth of the analysis was based on the information provided by the participants and therefore may not be comprehensive across all themes. The findings of the research have not been prioritised as this is specific to each person.

Research participants requested that follow up interviews be conducted in 12–24 months to track their progress and to see whether anything has changed.

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[1] Defined as speaking a language other than English at home.

Key findings

Many people with arthritis experience disability, with more than one-third of participants (37 per cent) reporting that their arthritis always limits their ability to engage in daily activities, and a further 54 per cent reporting that it sometimes limits their ability to engage in daily activities.

People with arthritis report significantly lower wellbeing compared with the general Australian population with the greatest adverse impact occurring in the domains of health, employment and finances.

The impairment associated with arthritis varies significantly, depending on the type and severity of the condition, the presence of other health conditions, and the time since diagnosis. The level of disability experienced by people with arthritis also depends on a variety of factors, including access to informal and formal support, flexibility in the workplace, and the availability of measures for social protection.

Where arthritis causes disability, people become socially excluded across one or more and sometimes all life domains – study, work, family and social participation. In particular, people's capacity to work is adversely affected by arthritis, with implications for their ability to meet the often high costs of managing their condition and to maintain an adequate standard of living.

People with arthritis-related disability may require short-term, long-term or permanent access to formal support, including both services and financial support. They have different needs which cannot be addressed with one response; responses need to be flexible to suit individual needs and circumstances.

Arthritis not only affects the person who has the condition, it also affects their carers, family, neighbours and friends, who often provide physical, emotional and financial support. The impact can include loss of income due to caring responsibilities, changes to relationships (e.g. partners become carers), reduced social participation, and a lower overall quality of life.

Access to financial support, appropriate health care and formal care appears to reduce the barriers experienced by people with arthritis in their ability to engage in daily life activities.

Personal wellbeing

People with arthritis recorded significantly lower wellbeing scores compared to the general Australian population (mean score of 64.0 compared to 77.6). Significantly lower wellbeing scores were evident across all domains but scores were substantially lower in the area of health (46.7 compared to 74.6).

The wellbeing of carers of people with arthritis was also significantly lower than that of the general population (66.0 compared to 77.6) and was similar to that of the people they support.

Health

The research investigated people's experience, and the barriers and facilitators to accessing quality, appropriate health care (physical, emotional and psychosocial), from initial diagnosis to ongoing care. The research found:

- Substantial delays between first symptoms of arthritis and diagnosis were common. Two-thirds of survey participants experienced delays of longer than 12 months to receive a diagnosis and of these, half were diagnosed five or more years after first symptoms presented.
- The quality of treatment provided to people with arthritis varied from no treatment ('it's age' or 'it's growing pains') to comprehensive treatment, either by a general practitioner, specialist or both. The quality of information provided to people about their disease and its treatment also varied widely.
- The cost of medications used to treat the disease and relieve symptoms was high, both in terms of the cost of individual medications and the number of different medications and supplements required, not all of which are subsidised under the Pharmaceutical Benefits Scheme (PBS) for people with arthritis.
- Almost half of participants had another health condition or disability which complicated the management of their arthritis and vice versa, particularly in relation to medication.

- Participants reported that pain and fatigue were overlooked in the treatment of their arthritis and few participants were offered options or advice on managing these symptoms.
- Effective arthritis management usually requires a team of health care professionals but accessing them is often difficult and expensive. Participants also reported that health services were complex and fragmented, and that they experienced difficulties navigating services and finding an appropriately skilled provider that met their needs.
- Living with arthritis adversely affected emotional wellbeing both for the person with arthritis and their carer, and this was often ignored in their treatment plan.

Habilitation

The research investigated people's access to habilitation and rehabilitation.[2] The research found:

- Nearly all participants (95 per cent) reported that their arthritis limited their ability to engage in daily activities, with 37 per cent reporting that they were always limited and 54 per cent reporting that they were sometimes limited in their ability to engage in daily activities due to their condition.
- Participants who identified as either always or sometimes having limited ability to engage in daily activities as a result of their arthritis then identified which activities were most affected: 34 per cent said their arthritis had a severe or profound impact on being able to manage their home or garden, 22 per cent on being able to undertake domestic activities, and 5 per cent on undertaking basic personal care.
- Participants reported making a range of changes to their living circumstances to accommodate their arthritis, from buying aids and equipment, modifying their homes, to relocating to more accessible homes.

Work and study

The research investigated people's experience and the barriers and facilitators to accessing and maintaining employment and study. The research found:

- Participants reported that the ability to participate in the workforce was important for social participation as well as to meet medical costs and maintain an adequate standard of living.
- Of the participants who were of working age (aged less than 65 years, 63 per cent), 74 per cent were employed full or part-time (57 per cent full-time and 43 per cent part time), 37 per cent were not in the labour force, and 15 per cent were studying full or part-time.
- The labour force participation rate for survey participants was 44 per cent, compared to the national participation rate of around 65 per cent. People who were younger when the condition started were more likely to be out of the workforce than those with onset at a later age.
- 67 per cent of all participants reported that arthritis had affected their work or study, now or in the past; 23 per cent reported that they were permanently unable to work or study because of their condition; 68 per cent were restricted in the type of work or study they could do; and 65 per cent were restricted in their hours of work or study. In addition, 35 per cent reported that they required workplace modifications and 14 per cent reported that they needed ongoing assistance to participate in work or study.
- Nearly all participants of working age who were not in the labour force reported that arthritis had affected their participation in the workforce (93 per cent). They were also more likely than those who were employed to report that their arthritis had restricted the type of work or study they could do (79 per cent) or the hours they could work (72 per cent). Half of participants who were not in the labour force reported that they were permanently unable to work or study because of their arthritis.

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[2] Habilitation is services that help a person learn, keep, or improve skills and functional abilities that they may not be developing, for example using a cane, guide dog or sign language. Rehabilitation is services that help a person improve skills that have been lost, for example regaining lost skills or functioning after a stroke or head injury.

- For participants of working age who were not in the labour force, almost half were 55-64 years old, i.e. close to retirement age.
- 43 per cent of research participants had retired, of whom 25 per cent were under the age of retirement – this may include people who planned to retire early and those who were forced to retire early because of their arthritis.
- Participants with osteoarthritis, rheumatoid arthritis and other forms of arthritis were less likely to be in the labour force compared with other participants. People who were not in the labour force were also more likely to have experienced symptoms at a much younger age than those who were employed.
- The extent to which people were able to work or study depended on whether they needed to and were able to work flexibly, work reduced hours, or have access to a modified workplace.

Standard of living and social protection

The research investigated the implications of people's lived experience of arthritis in terms of being able to attain and maintain an adequate standard of living for themselves and their family. The research found:

- Participants reported that the financial consequences of arthritis were detrimental due both to the high costs associated with living with the condition and the loss of income due to reduced capacity to work. The financial impact of having arthritis also affected other areas of their social participation and wellbeing.
- Costs included ongoing medical care, the high and continual cost of medication, aids and equipment, home help and maintenance services, personal care and transport.
- Two-thirds of participants said that they were financially worse off due to having arthritis; 16 per cent reported that they struggled to meet their expenses due to the financial impact of their arthritis, while 5 per cent reported that they were much worse off and needed financial support. Many of the participants reported compromising their ongoing health care and other basic needs (food and utilities) to meet the cost of medication.
- 33 per cent of participants relied on public financial support (e.g. Disability Support Pension or Age Pension). Of those receiving public financial support, 21 per cent were under 65 years of age and therefore were likely to be receiving disability or other support rather than the Age Pension.
- Participants reported that accessing social protection was complex and difficult. Participants noted that available support was not flexible enough to respond to fluctuations in the severity of their disease (disease flares).
- Government support for ongoing medical costs was identified by participants as a high priority, particularly given the chronic nature of arthritis, the fluctuations of the disease, and the high cost of medication and treatment.

Family and social participation

The research investigated people's experience, barriers and facilitators of being included and participating in their family and community. The research found:

- The extent to which people's family and social participation was affected by their arthritis depended on the level of impairment caused by their condition, personal circumstances, and the availability of informal and formal support at home and in their place of work or study.
- Nearly all participants (84 per cent) identified informal support from immediate family members as their main source of support for personal care, domestic activities and managing their arthritis. This was due to the proximity of family, the lack of access to flexible services, or because they could not afford formal services due to reduced income.
- For people whose arthritis caused significant disability, greater formal support at home, work or study would improve their social participation.
- Arthritis affected children – they may have arthritis themselves or they may have a sibling or parent with arthritis, affecting family dynamics or requiring them to take on caring responsibilities.

- Some women chose not to start a family because of their arthritis, as the prolonged period off their medication could have long-term effects on the severity and prognosis of their condition.
- The impact of arthritis was not limited to the people with arthritis but also affected their carers, family, neighbours and friends:
    - physically – especially older carers who are also likely to have arthritis or other health conditions
    - emotionally – in terms of isolation, changed relationships, financial hardship, and the impact on their own social participation
    - financially – in reducing or limiting their capacity to work.

Services and support needs

Participants identified a number of service and support needs concerning information requirements, informal support (family and friends, community and arthritis support groups), formal support (health care, medication, social protection and home care), and other areas (employment, home modifications, equipment, and public awareness).

- People with arthritis, their families and carers, need access to better information about their condition, including: medication and side effects; managing pain and fatigue; support groups and emotional support available; aids and equipment and how to source them; and the availability of social and disability services and how they can be accessed.
- Some participants with arthritis rely heavily on informal support, in particular from family and friends. Family and friends need to be supported to be able to sustain this role.
- Increased community awareness and understanding of arthritis – including amongst health practitioners, policy makers and employers – could also improve support for people with the condition.
- Local or online support groups help meet the needs of people with arthritis and could be expanded to target specific age groups and conditions.
- There is a clear need to identify and improve formal support, from providing better ongoing health care beyond diagnosis, increasing the coverage of necessary medications under the PBS, to improving awareness of the disabling impact of arthritis in the provision of social protection and social services.

Increasing recognition in the broader community of the nature and impact of arthritis, and the fact that it affects people of all ages – and not just older people – would help address many of the service and support needs identified.

Implications of this research

This report reflects the voices of people with arthritis who are trying to hold down a job, raise a family, and participate in the life of the community, while managing the disabling effects of their condition. They face significant challenges due to the complexity and fragmentation of health services, inflexibility in the social support sector, and limited awareness in the community of the impact of living with arthritis.

Many people with arthritis experience disability and require support – both short-term and long-term – depending on the nature of the condition, the impact it has on them, and their personal circumstances.

It is not clear to what extent the National Disability Insurance Scheme (NDIS) will support people with arthritis or whether any existing support services provided will be affected. A risk is that where services (from State and other providers) are transitioning to the NDIS, access to support currently available might be reduced.

This research suggests that:

- The disabling impacts of arthritis need to be recognised in the community as well as by government, service providers, employers and educators.
- The NDIS should recognise the severely disabling and fluctuating effects of arthritis. Some people with arthritis will need NDIS individual packages.
- Other formal support services need to be identified for people with arthritis, made available both flexibly and long-term, and be provided to people who do not qualify for an individualised package under the NDIS but who still need formal support.
- The provision of services should be monitored during the transition to the NDIS to ensure that services are maintained for people with arthritis who require them.

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