“The financial impact is depressing and anxiety inducing”: A qualitative exploration of the personal financial toll of arthritis

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Abstract

Objectives: The financial experience faced by working-age people with arthritis include living below the poverty line for many. Financial distress amongst people with arthritis is known to contribute to poorer health outcomes, including high psychological distress and more severe pain. Despite the demonstrated societal cost of arthritis care and management, the personal costs borne by the individual are not well understood. The aim of this study was to explore the perceived financial impacts of living with arthritis amongst younger adults (defined as those aged 18 – 50 years).

Methods: A qualitative descriptive study design was used. Participants with inflammatory arthritis or osteoarthritis were recruited from the community, including urban and rural settings. An interview schedule was developed, informed by existing literature, which was piloted prior to
data collection. Deductive and inductive coding techniques were used to identify financial-related themes arising from the data.

**Results:** Semi-structured interviews were conducted with 21 adults (90% female) with a mix of arthritis conditions including rheumatoid arthritis, psoriatic arthritis and osteoarthritis. Four themes were identified: direct arthritis-attributable medical costs, indirect arthritis-attributable costs, insurance and pension costs, and broader financial impacts on the family. Non-subsidised costs were frequently referenced by participants as burdensome, and existed even within the publically-funded Australian healthcare system.

**Conclusion:** Adults with arthritis experience significant arthritis-attributable financial burden and related distress. Financial concerns should be actively identified and considered within shared clinical decision making, in order to provide more patient-centred care for these individuals.

**Significance and Innovations**

- Adults with arthritis experience financial hardship associated with their disease, and many live below the poverty line despite access to a publically-funded healthcare system.
- Financial impacts identified by participants included for the costs of clinical care and medication, reduced employment wages, and burden on the family financial situation.
- These financial implications were associated with considerable distress and anxiety, highlighting the wide-ranging impacts of arthritis on adults.
- Discussion of arthritis-related financial concerns should form part of shared clinical decision-making, to facilitate patient-centred care.
Introduction

Arthritis is increasingly recognised as a disease that affects people of working age (1). In Australia, based on the most recent National Health Survey data, it is estimated that 24% of people with arthritis are aged 25 – 54 years – the peak income-earning years for most (2). Given the breadth of biopsychosocial impacts associated with arthritis, including pain and reduced physical function, and higher levels of anxiety and depression, individuals with arthritis are likely to experience career disruption, reduced work productivity and financial burden sequelae (3-6).

The economic impacts of arthritis in working-age populations are profound, as many transition into early retirement due to the condition (7-9). At a population level, the sequence of arthritis-attributable early retirement and welfare-related costs in working-age persons cost Australia
$AUD7.2 billion in 2015. By 2030, this is projected to increase to $AUD9.4 billion (10). At a personal level, the median weekly income for an individual with arthritis is $AUD333.13 (11). In contrast, the poverty line for a single adult living alone is $AUD433.00 (12). Financial distress is known to contribute to poorer health among people with lifelong illness and pain, including high psychological distress and severe physical pain (13-15).

A limited body of research provides preliminary insights into the personal financial burden borne by working-age people with arthritis. Evidence suggests that individuals with rheumatoid arthritis (RA) who are aged less than 65 years spend significantly more on self-management measures and prescription medication than people with RA aged over 65 years, to improve their functional capacity and assist with activities of daily living (ADLs) (16). In Australia, females retiring early due to arthritis have an average of 83% less savings to fund their retirement compared to females who work to retirement age (17). It has been estimated that the financial burden on individuals with arthritis and musculoskeletal conditions is higher than the burden experienced by individuals with other lifelong conditions (18). Individuals living with arthritis report a high number of general practitioner (GP) appointments for prescription medications, higher psychology-related healthcare costs (the prevalence of major depression is 1.6 times higher in people with arthritis than their healthy peers), and additional pain management costs (19, 20).

Direct healthcare costs can include general practitioner (GP) and specialist visits (for example, rheumatologists) as well as consultations with allied health professionals (for example, physiotherapists) (21). Pharmaceuticals, diagnostic tests, dietary supplements and/or natural therapies, and supervised exercise programs further add to the cost burden (21). In addition to direct costs, indirect costs include reduced number of hours worked, forced early retirement, home modifications, travel to and from healthcare appointments, and contributions from family members (for example, unpaid carer responsibilities) (22).

The personal financial burden borne by working age people with arthritis is yet to be explored in depth. The current study sought to examine the perceived financial impacts of living with arthritis amongst younger adults (defined as those aged 18 – 50 years).

Methods

Design

A qualitative descriptive study was undertaken in 2019 to explore the perceived work and financial impacts of arthritis on adults. A separate paper has previously reported findings around
work participation restrictions and workplace impacts (6). This paper focuses on the financial impacts. Human Research Ethics approval was granted from the Monash University Human Research Ethics Committee (Project ID 12657) in May 2018. Reporting of the study was undertaken according to the COnsolidated criteria for REporting Qualitative research (COREQ-32) (23).

The Australian Healthcare System: An Overview

Australia adopted a taxpayer-funded universal healthcare scheme (known as Medicare) in 1984 (24). It is comprised of the Medicare Benefits Schedule, and the Pharmaceutical Benefits Scheme. The Medicare Benefits Schedule is a list of health services subsidised by the Australian government. There are over 57,000 items which provide benefits for a range of services, including specialist consultations, diagnostic tests, and procedures (25).

The Pharmaceutical Benefits Scheme subsidises the costs of over 5,000 medications. Via the scheme, the Australian government contributes the majority of the medication cost, and the consumer pays the remaining fee which is termed the out-of-pocket cost (24).

Australia also has a parallel private health system, supported by private health insurance policies, that individuals can choose to purchase alongside access to Medicare (24). Private hospital insurance covers the cost for some (or all, depending on the healthcare practitioner) treatment in a private hospital. Private ancillary insurance covers other health services not always included as part of Medicare, including dental treatment and other allied health services and programs (24). The most recent data indicate that 45.1% of the Australian population were covered by private health insurance in 2018 (26).

Participants

Males and females aged 18 – 50 years who reported a diagnosis of inflammatory arthritis (IA) or osteoarthritis (OA) by a registered medical practitioner (GP or rheumatologist) and were living in Australia were eligible to participate. The study was advertised through arthritis consumer organisations, university staff newsletters, and social media. Individuals with a range of arthritis disease types, genders, employment status, geographic locations (urban, rural) and socioeconomic status were recruited via a purposive sampling frame. Those who expressed an interest in participating were provided with further information by the lead researcher (DB) and asked to complete a brief screening questionnaire to confirm their eligibility.
Females who were pregnant were excluded from the study, as it was anticipated that they might have additional concerns related to pregnancy (27, 28). Those who had an unconfirmed arthritis diagnosis, were unable to communicate in English, or were unable or unwilling to provide consent were also ineligible to participate.

Data Collection

An interview schedule informed by existing literature and validated framework was developed by DB and DA (1, 29). DB has lived experience with an inflammatory arthritis condition, and in this context was able to assess the relevance of the interview schedule (30). As this is one of the first instances of arthritis-attributable costs for the individual being explored using a qualitative approach, interview questions were intentionally broad. The interview guide incorporated open-ended questions and probing questions in relation to financial factors (Table 1). Data collection was also iterative, and probing questions were used based on the participants’ responses. Responses related to new financial themes captured in early interviews were incorporated as additional questions in later interviews. All individual, semi-structured interviews were conducted via telephone by the same researcher (DB) who has experience in qualitative data collection. All interviews were audio-recorded to enable verbatim transcription. Researcher reflections were captured in writing during the data collection process and used to optimise the conduct of subsequent interviews but are not reported here.

INSERT TABLE 1 HERE

Data Analysis

A thematic analysis approach was adopted. Thematic analysis is a method used in qualitative research to determine, analyse, and compile themes from participant-oriented data (31). Thematic analysis is useful for contextualising similarities and differences across a range of participant perspectives, and to highlight unanticipated insights and novel data (31). As this research was exploratory and included a sample with varying arthritis-related experiences, a thematic approach to data analysis was suitable (32). Data analysis commenced alongside data collection, to enable themes identified in earlier interviews (interviews 1 – 5) to be explored in
subsequent interviews. Participant recruitment and data collection ceased when data saturation was evident (33).

NVivo Version 12 was used to support data management and analysis via a process of inductive and deductive coding methods using open, axial, and thematic coding (34). Open codes were generated by looking for initial concepts from participants about their arthritis-attributable financial experiences. Axial coding was conducted to connect common themes identified by participants. For example, each participants’ individual financial concerns were analysed collectively, to identify similar patterns. Using deductive coding, themes that correspond to the three interview guide topics were identified. Coding and data analysis were conducted by DB. To ensure construct validity, the emergent framework of codes was continuously presented back to a multidisciplinary research team, comprised of qualitative researchers and physiotherapists specialising in arthritis care (35). Where participant quotes are cited, these are provided verbatim. All monetary amounts are expressed in Australian dollars (1 AUD= 0.67 USD).

Results

Thirty-nine expressions of interest to participate were received. Five people could not be contacted, and within our purposive sampling approach, six others were not recruited to prevent over-sampling of specific arthritis conditions. Of the remaining 28 (71.8%) people who were screened for eligibility, 25 (64.1%) participants were eligible. Of the 25 eligible participants, 21 (53.8%) were included in the final sample (the remaining four participants declined to participate.)
due to other commitments or illness). The 21 interviews ranged in length from 30 minutes – 95 minutes. Data saturation was reached in the final four interviews when it became apparent that no new themes were emerging.

Participant characteristics are shown in Table 2. The majority of participants were female (90.0%), and aged over 30 years (62.0%). Over one third had been diagnosed with RA (38.0%), with psoriatic arthritis being the next most common diagnosis (19.0%). Almost one third of participants lived with their partner and children (29.0%). Nearly half the participants had an undergraduate university degree (43.0%). Nearly three quarters participants had private health insurance (71.5%). Only one third of participants were in full-time paid employment (33.5%). One third of participants were in part-time or casual paid employment (33.5%). Fifteen percent of participants reported they were unable to work because of their arthritis.

**INSERT TABLE 2 HERE**

Four major themes were evident from the interviews (Table 3): 1) the financial burden of direct arthritis-attributable healthcare costs; 2) the unexpected financial burden of indirect costs of living with arthritis; 3) benefits versus the financial burden of paying for insurance; and 4) and the broader financial impacts on the family.

**INSERT TABLE 3 HERE**
Theme 1: The financial burden of direct arthritis-attributable medical costs

Participants reported that the out-of-pocket or non-subsidised costs associated with arthritis-attributable medical expenses were “bloody depressing” and “anxiety inducing”. In contrast to an acute or short-term illness, participants emphasised the sustained financial burden due to the lifelong nature of arthritis: “it’s the rest of your life you’re paying for this stuff”. The greatest expenditure incurred was for specialist rheumatologist consultations, although the reported figures varied between participants. For some participants, rheumatologist appointments incurred no out-of-pocket costs, as they accessed specialist consultants through the public hospital system. One participant stated that they had an initial consultation with a rheumatologist whose fees were $AUD500, whereas the majority of participants reported paying approximately $AUD200 per appointment. Regardless of the charge, many perceived specialist consultation to be costly: “seeing your rheumatologist all the time is expensive”. For those with psoriatic arthritis, seeing a dermatologist to manage the psoriasis component of the condition was considered an additional financial burden.

In addition to rheumatologists’ fees, participants highlighted the significant expense associated with medications and allied health services. Many expressed gratitude for publicly-funded Medicare healthcare, as illustrated by a quote from one participant: if Medicare didn’t cover my etanercept it would be a thousand dollars a fortnight, stupid money”. Although participants acknowledged that medications were made more affordable under the Pharmaceutical Benefits Scheme, they noted the substantial expense associated with multiple concurrent medications: “when you’re on two or three that’s a monthly cost that adds up”. Participants described using allied health to help manage arthritis-attributable symptoms, but “when the physio costs $65.00 and I’m looking at probably the next ten years of things like physio and acupuncture”, the non-subsidised costs become burdensome. One participant described paying for preventative health services, as “I need to proactively improve my health and arthritis from a non-drug related perspective… particularly being anxious in the workplace about my limitations about being able to pick up things”.

Theme 2: The unexpected financial burden of indirect arthritis-attributable costs

Participants stated that arthritis-related physical symptoms caused career disruptions and hindered their ability to work full-time. Many specified that they “weren’t able to work for many years after diagnosis”, and that even years after diagnosis “it still works better for me to work part-time”. As a result, a common sentiment was that “it would be nice to have some extra money”. For some
participants, having less money was compounded by unanticipated costs associated with the invisible nature of arthritis. For example, participants explained that it was easier for them to drive to work and social events than to take public transport, as “standing on the train my legs actually get quite sore”. Fellow commuters tend to “look for visual symptoms like crutches or walking sticks” and as a result, “no one's going to give up their seat because obviously they assume nothing's wrong”. Participants therefore “often just end up driving to events”, which creates additional costs where you “have to pay for parking”, and need “extra money for fuel because it's easier to drive places than to walk or take the train”.

In addition to transport costs, participants described financial constraints to the extent that they were unable to afford non-medical assistance with arthritis-related physical limitations. For example, some participants’ symptoms inhibited them from completing ADLs, yet they were unable to afford professional assistance. Several participants described “scrounging pennies” to pay for home-based ergonomic devices, from less expensive aids such as a “basket on wheels so if the washing needs to be done I can carry it”, to a more expensive “gadget that lifts the bottom shelf of the dishwasher so you don't have to bend over”.

**Theme 3: Benefits versus the financial burden of paying for insurance**

Participants reported that private health insurance was one of their largest health-related expenses. Individuals or families often choose to purchase private health insurance in case of injury, or flare up of symptoms. However, those living with arthritis perceived private health insurance as essential expenditure, stating “I can't afford to not have private health”. Many confirmed that they “took out private health insurance because of arthritis”, and that this was “because if I need an operation I can get it done tomorrow and not wait for 12 months when you're in desperate agony”.

Over a quarter of participants did not have private health insurance, as “contemplating the premiums would be a lot higher for someone like me with arthritis and I already have no money”. Participants who stated they were unable to afford private health insurance were frustrated that others are allowed to access both the public and private healthcare systems simultaneously. Many expressed sentiments such as “we don't really have the money for health insurance but I probably would like to have it because then I can have my neck fixed straight away” and that as a result “it's frustrating that people can double dip and go public or private, financially it's abuse”.

In addition to private health insurance, other insurance costs were perceived to weigh heavily on people with arthritis. Participants were frustrated that travel and life insurance was more expensive due to the presence of a pre-existing medical condition. Many were left uninsured and
expressed concern at the potential financial burden placed on their families. Participants fretted over their limited funds and their frustration at minimal government compensation in the form of disability pensions and healthcare cards to provide those living with lifelong conditions supplementary income, and reduced medical costs. However, participants stated that “I was on a disability pension for the arthritis” but that it was rendered futile when “not a lot of doctors do a special concession rate for people on a pension”.

**Theme 4: Broader financial impacts on family**

Alongside concern for their own finances, participants voiced distress about the broader financial impacts of arthritis on their families. Younger participants (those aged 18 – 21 years) explained that they lived at home with “a supportive family that would help me out in any situation”, but that “it’s still a bit concerning that I’m not paying for my own appointments and my parents shouldn’t have to”. Those who were slightly older (aged 25 – 30 years) acknowledged that their parents noticed when they were having a flare-up, and that they would “try and pitch in with costs where they can but I don’t like it because they should enjoy their retirement without worrying about my financial state”.

In contrast to children placing financial pressure on their parents, participants who were parents expressed similar worry about imposing a financial burden on their own children. For example, one participant explained, “I don’t want my children to think that they can’t have careers because they have to look after me if I’m much worse when I’m older”.

The financial consequences of living with arthritis extended into broader implications for the whole family. For example, living on a reduced income for an extended time meant that families were unable to take holidays, mortgage repayments had to be defaulted or extended, and children were forced to enter the workforce earlier than they otherwise would have. As one participant explained, “we live like grey nomads [but] in Australia, no overseas travel, with a chronic condition attached to it”.
Discussion

Arthritis is clearly associated with profound financial impacts and associated financial distress among adults. This study is one of the first to examine these financial concerns from an in-depth qualitative approach, involving a community-based sample of people with different arthritis conditions. Our findings indicate that a range of financial impacts and concerns, including direct arthritis-attributable medical costs, and other impacts that lie outside of direct healthcare, characterise people’s experiences of living with arthritis.

Study participants highlighted the high fees for access to rheumatologists. The financial burden of paying for specialist appointments is topical in Australia: a recent review found that the average non-subsidised cost for an initial rheumatology consultation – net of the subsidised Medicare rebate – is $AUD120.00 (36). It has been found that the cost of medical intervention is not related to improved health outcomes or superior quality of care (37). Those with lower health literacy levels may be vulnerable to excess healthcare expenditure and financial burden without receiving best-practice care (38, 39). A taskforce has been developed and aims to ensure that all Medicare Benefits Schedule items provide real clinical value, or high-value care, and do not expose patients to unnecessary expense (36).

In addition, participants expressed their surprise at the expense of non-subsidised allied healthcare costs incurred through the outpatient public hospital system, despite access to universal healthcare in this country. Due to changing health needs, increasing healthcare costs, health inequities, and complex health conditions, patients are shouldering growing out-of-pocket costs (40). However, within the ‘fee-for-service’ payment model, health professionals are permitted to set their own fees (which are typically above the schedule fee that is reimbursed), this can lead to high non-subsidised costs for some patients (41).

Evidence suggests that the current out-of-pocket costs for people living with lifelong illness in Australia are strongly associated with experiencing poverty (42). Similar trends are documented in Nordic countries, which also have combination public and private healthcare systems (43, 44). In Australia, growing out-of-pocket costs are partially attributed to increased uptake of private health insurance due to lengthy waiting periods for a rheumatology, pain medicine or surgery consultation through the public system (45, 46). Participants also highlighted their fiscal concerns
extending beyond direct healthcare costs, including reduced capacity to pay for their mortgage, childcare and the impacts on travel and life insurance.

There is emerging data on the effects of lifelong illness on financial domains beyond medical expenses. People living with coronary artery disease have outlined challenges relating to driving costs where public transportation or walking is unfeasible (47). People affected by Types 1 and 2 diabetes have explained that only by limiting expenditures on non-medical related items were they able to afford medication (48). However, to the best of our knowledge, this study is one of the first dedicated to examining the perceived financial burden of living with arthritis.

It is perhaps unsurprising that adults with arthritis face much broader personal economic challenges beyond their direct medical costs. It is well documented that this population have shorter work careers, are less confident to pursue career progression opportunities, and earn significantly less throughout their income-earning years than their healthy peers (6, 49). Lower work participation rates and financial sequelae present as concurrent challenges to navigate for people with arthritis. Through reporting these fiscal challenges, our findings provide a starting point for understanding the concerns of younger populations with arthritis, beyond the health impacts. In particular, education and support from arthritis consumer organisations or other advocacy groups may be provided to, or accessed by, clinicians treating people of working age with arthritis. Clinicians need to be cognisant that their patients may be experiencing financial distress, and that identifying these concerns as part of routine clinical care can help inform shared decision making, particularly as it relates to accessing interventions or services that are high-value, and identify available services that may be feasible (for example, referring a patient to a community physiotherapy program, versus a private practice).

**Strengths and Limitations**

As our study was exploratory in nature, it was important to examine broad arthritis-attributable financial experiences and we were able to recruit a heterogeneous participant sample to achieve this. Our recruitment strategy spanning arthritis consumer organisations, university networks, and clinical settings generated a sample that was diverse across age and disease characteristics. In-depth semi-structured interviews were used to elicit detailed data from participants. However, we did not directly ask about non-medical related costs (for example, home modifications, childcare), although these were reported by some participants during the interviews. In this context, we may have under-represented this theme in the analysis.
Qualitative research is representative of participants’ experiences, however, our research cannot be generalised to all people’s arthritis-attributable finances. Two thirds of participants were university-educated, which may indicate higher income levels amongst our sample compared to the broader population with arthritis. We also recognise that a relatively high proportion of our sample had private health insurance, compared with the general population, but that this does not necessarily reflect the socioeconomic status of our sample given ongoing government initiatives designed to lower the cost of private health insurance and improve uptake. We also acknowledge the potential for participant bias, where those with higher financial burden may have been more likely to volunteer to be a part of this research. There was an oversampling of females (reflecting the demographics of arthritis); a potentially important area of future research, therefore, will be to explore these issues amongst males with IA and OA.

Conclusion

This study highlights the spectrum of ongoing direct and indirect costs borne by adults living with arthritis conditions. The in-depth interviews provided novel insight into the range of financial concerns experienced by younger patient groups and the personal distress associated with these. These findings can be used to raise awareness of key fiscal issues relevant to adults with arthritis, and to educate clinicians about the wide-ranging impacts of arthritis beyond physical symptoms.
References


27. Briggs AM, Jordan JE, Ackerman IN, Van Doornum S. Establishing cross-discipline consensus on contraception, pregnancy and breast feeding-related educational messages and clinical practices

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Table 1: Interview Guide as mapped to arthritis-attributable financial factors

<table>
<thead>
<tr>
<th>Topic</th>
<th>Open Question/s</th>
<th>Probing Question/s</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Current financial factors</strong></td>
<td><strong>(direct costs)</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>What do you currently spend your money on to help manage your arthritis?</td>
<td>What experiences have you had paying for medical and specialist appointments?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>What experiences have you had paying for medications and other types of tablets?</td>
</tr>
<tr>
<td></td>
<td>Do you pay for different types of insurance (health, life, travel) because of your arthritis?</td>
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<tr>
<td></td>
<td></td>
<td>What level of financial distress do these out-of-pocket costs cause?</td>
</tr>
<tr>
<td><strong>Current financial factors</strong></td>
<td><strong>(indirect costs)</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Do you have costs that are not directly attributable to arthritis, but that you find affect you financially?</td>
<td>Are you still able to work, and if so, have you had to take time off work for medical appointments or sick days?</td>
</tr>
</tbody>
</table>
Do you have the level of productivity that you would like to at work? Has this changed since your arthritis diagnosis?

Has missing work, or having reduced productivity at work, led to any financial concerns?

What concerns do you have moving forward about continuing to produce an income?

What concerns do you have about the progression of your arthritis, and the out-of-pocket costs associated with that?

Are you worried about the financial burden that your arthritis may place on the people around you?

Table 2: Participant Demographics

<table>
<thead>
<tr>
<th>Demographics</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender, female</td>
<td>19 (90.0)</td>
</tr>
<tr>
<td>Age bracket</td>
<td></td>
</tr>
<tr>
<td>18 – 30 years</td>
<td>8 (38.0)</td>
</tr>
<tr>
<td>31 – 40 years</td>
<td>6 (28.5)</td>
</tr>
<tr>
<td>41 – 50 years</td>
<td>7 (33.5)</td>
</tr>
<tr>
<td>Highest education status</td>
<td></td>
</tr>
<tr>
<td>High School</td>
<td>2 (9.5)</td>
</tr>
<tr>
<td>Certificate / Diploma</td>
<td>5 (24.0)</td>
</tr>
<tr>
<td>Undergraduate University degree</td>
<td>9 (42.5)</td>
</tr>
<tr>
<td>Postgraduate University degree</td>
<td>5 (24.0)</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>----------</td>
</tr>
<tr>
<td><strong>Current living status</strong></td>
<td></td>
</tr>
<tr>
<td>Lives with partner/spouse and children</td>
<td>6 (28.5)</td>
</tr>
<tr>
<td>Lives with partner/spouse</td>
<td>4 (19.0)</td>
</tr>
<tr>
<td>Lives alone</td>
<td>3 (14.0)</td>
</tr>
<tr>
<td>Lives with parents</td>
<td>3 (14.0)</td>
</tr>
<tr>
<td>Lives with other adults (non-family members)</td>
<td>3 (14.0)</td>
</tr>
<tr>
<td>Lives with own children</td>
<td>2 (9.5)</td>
</tr>
<tr>
<td><strong>Current employment status</strong></td>
<td></td>
</tr>
<tr>
<td>Full time, paid work</td>
<td>7 (33.5)</td>
</tr>
<tr>
<td>Part time/casual, paid work</td>
<td>7 (33.5)</td>
</tr>
<tr>
<td>Student</td>
<td>3 (14.0)</td>
</tr>
<tr>
<td>Unable to work because of arthritis</td>
<td>3 (14.0)</td>
</tr>
<tr>
<td>Unemployed or looking for work</td>
<td>1 (5.0)</td>
</tr>
<tr>
<td><strong>Arthritis diagnosis</strong></td>
<td></td>
</tr>
<tr>
<td>Rheumatoid Arthritis</td>
<td>8 (38.0)</td>
</tr>
<tr>
<td>Psoriatic Arthritis</td>
<td>4 (19.0)</td>
</tr>
<tr>
<td>Osteoarthritis</td>
<td>2 (9.5)</td>
</tr>
<tr>
<td>Ankylosing Spondylitis</td>
<td>2 (9.5)</td>
</tr>
<tr>
<td>Seronegative Inflammatory Arthritis</td>
<td>2 (9.5)</td>
</tr>
<tr>
<td>Combination of Arthritis types</td>
<td>2 (9.5)</td>
</tr>
<tr>
<td>Juvenile Idiopathic Arthritis</td>
<td>1 (5.0)</td>
</tr>
<tr>
<td><strong>Private health insurance status</strong></td>
<td></td>
</tr>
<tr>
<td>Yes (own policy)</td>
<td>12 (57.5)</td>
</tr>
<tr>
<td>Yes (parents' policy)</td>
<td>3 (14.0)</td>
</tr>
<tr>
<td>No</td>
<td>6 (28.5)</td>
</tr>
</tbody>
</table>
Table 3: Arthritis-attributable themes, subthemes, and illustrative quotes

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub-theme</th>
<th>Illustrative quote(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>The financial burden of direct arthritis-attributable healthcare costs</td>
<td>Medical specialist costs</td>
<td>I see it [the rheumatologist] as a money-grabbing thing, so I go every six months. They feel your joints and they go yeah, see you in three months’ time. Like, I’ve just sat in your waiting room for two hours, you’ve just charged me $200 for that two hours of sitting for like a three minute appointment. Seeing your rheumatologist all the time is expensive. (Participant 7, F, 41 – 50, RA)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>The rheumatologist that I’m seeing is very expensive and the rebate isn’t huge. (Participant 11, F, 41 – 50, RA)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>The dermatologist who I went to for my psoriasis did not recognise the fact that I had arthritis as well… I’ve probably paid for his speedboat since then… That’s probably where he could have said hey, I can’t help you. (Participant 2, M, 41 – 50, PsA)</td>
</tr>
<tr>
<td></td>
<td>Allied health costs</td>
<td>I’ve been referred to strengthen my core through Pilates because I’ve got quite a lot of wear and tear in my spine. So just this week I’m going to start Pilates with a physio. The cost is quite shocking and I suppose that’s the thing that’s really frustrating. (Participant 15, F, 31 – 40, CA: RA, OA)</td>
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<td>I’ve seen a Bowen therapist before, she’s quite good, she is quite expensive though, so it hasn’t been really on my top priority list. (Participant 9, F, 18 – 30, OA)</td>
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<td>I used to see a physio and we’d do hydrotherapy. I don’t know why but I just sort of stopped. You know, it was quite expensive. (Participant 3, F, 18 – 30, RA)</td>
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| The unexpected financial burden of indirect costs of living with arthritis | I remember struggling to mow the lawns and things like that, and not being in a financial position to be able to pay someone to do it. (Participant 5, F, 18 – 30, AS).

I think if I didn’t have chronic illness we would probably have a lot more money. We probably would have paid off the house. (Participant 14, F, RA, 41 – 50).

We put a big extension on the back of the house for my arthritis, which we borrowed ... We owe a lot, it’s not good, it’s not manageable. (Participant 12, F, 31 – 40, PsA).

I couldn’t really get up in the morning so I went out and bought a new bed thinking that that might fix all the problems. I spent a few thousand dollars on buying a bed. I don’t think it helped at all. (Participant 21, M, 31 – 40, AS). |
| --- | --- |
| Medication costs | I recently did a budget and I added up all my medications. And then there’s calcium and fish oil and those sorts of things as well. Like I added all this up and it was like, $1,500. I was in the red and it made me realise that there’s actually quite a lot of money attached to having this condition. I actually have to budget for this. (Participant 12, F, 31 – 40, PsA).

I was fortunate growing up that my parents sort of paid for the medication. But now I realise wow, this stuff, not exactly the cheapest thing, and I’m a student, it’s a little bit more expensive. (Participant 1, F, 18 – 30, CA: RA, SLE) |
| **Benefits versus the financial burden of paying for insurance** | **Transport and parking costs** | I pay extra money for fuel because it’s easier for me to drive places than to walk. (Participant 10, F, 18 – 30, JIA).

When you’re on drugs that lower your immune system and you catch public transport – one year I got sick six times, so now I drive. And of course, I have to pay for parking which is really expensive too, so that’s another added cost. (Participant 15, F, 31 – 40, CA: RA, OA)

Parking, like when I was in hospital for seven months, parking cost us a fortune. We spent heaps on the parking, we didn’t save money at all with me being in hospital. Those parking costs just come right out of the budget. (Participant 7, F, 41 – 50, RA). |
| **Private health insurance** | **It is expensive – my mum says ‘are you planning any holidays?’ and I say ‘no, we’ve got private health insurance, we can’t afford all that’. (Participant 12, F, 31 – 40, PsA)** |
| **Travel and life insurance** | **Things like travel insurance; that tends to be a lot more expensive when I need that. So that’s definitely something I need to think about more when planning to travel. (Participant 9, F, 18 – 30, OA).** |

I got life insurance before I got the rheumatoid. It came with our credit card or whatever it was. They don’t know I’ve got rheumatoid. It’s so expensive. I got it before I had it, and nobody else will insure me. (Participant 7, F, 41 – 50, RA) |
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<tr>
<th>Broader financial impacts on the family</th>
<th>Disability pension and healthcare card</th>
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<td>Single income household</td>
<td>I am on a disability pension, like I think the full disability pension, they get about $800 a fortnight, but I get $200 a fortnight. (Participant 12, F, 31 – 40, PsA).</td>
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<td>I couldn’t get a healthcare card because I earn $20 more than I should. Ridiculous. I’m very fortunate that my partner promised to pay for my medical expenses. Otherwise I wouldn’t be able to afford it. (Participant 10, F, 18 – 30, JIA).</td>
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<td>Financial strain on parents and children</td>
<td>Obviously I can’t work. We are a single income family. Um, so that single income family, that does impact everything. Going away, it impacts where you can go, stuff like that. (Participant 7, F, 41 – 50, RA).</td>
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<td>Being on a single income we couldn’t really afford to put the kids in childcare every day, that sort of thing. (Participant 12, F, 31 – 40, PsA).</td>
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<td>Even though it is my parents’ role I do still worry about it. Because it is still very expensive and I’d hate to put a financial burden on my parents and my family. So yeah it is still definitely a concern, even though I’m not actually paying for it. (Participant 3, F, 18 – 30, RA)</td>
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<td>My son, he’s in year five of university now, and I think if I was ordinary I think he probably would have gone and got a job properly by now. He might have been able to have holiday or something, it would have been nice for him to have some extra money. (Participant 12, F, 31 – 40, PsA).</td>
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F: Female; RA: rheumatoid arthritis; CA: combination of arthritis types; OA: osteoarthritis; PsA: psoriatic arthritis; SLE: systemic lupus erythematosus; JIA: juvenile idiopathic arthritis; AS: ankylosing spondylitis
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