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Lived experience of out-of-pocket costs of health care and medicines by people with chronic conditions and their families in Australia: a systematic review of the qualitative literature

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ABSTRACT

Background: Despite Australia's universal health insurance scheme, Medicare, out-of-pocket costs (OOPC) for health care comprises 14 % of total health expenditure. People with chronic conditions spend a greater proportion of their incomes on health care than people without a chronic condition.

Objective: To review the qualitative literature examining experiences of OOPC of out-of-hospital care by people with chronic conditions and to discuss this in relation to current Australian health policy.

Methods: Systematic review and narrative synthesis of the qualitative literature examining OOPC for people with chronic conditions in Australia. Search: Pubmed, CINAHL Complete, Cochrane Library, PsycINFO and EconLit databases from 1999 to 10th April 2025.

Results: 37 studies met the inclusion criteria. Reduced or lost employment due to ill-health led to income loss, aggravating the financial burden of health management. While many people were able to access bulk-billing general practitioners, challenges in affording upfront and copayments for medical and allied health consultations, and medication costs were reported. Cost was the greatest barrier to accessing dental care. Trade-offs were described between health management and meeting basic living needs, particularly for people who earned too much to qualify for government welfare payments.

Conclusion: While Australian health policies effectively reduce the financial burden of health care for many people, distinct challenges exist for groups ineligible for concessional thresholds. Future research to identify the priorities and preferences of people with chronic conditions can further inform policy to improve the equity of health financing in Australia.

1. Background

Despite Australia having universal health coverage, Medicare, out-of-pocket costs (OOPC) for health care and medicines make up 14 % of total health expenditure [1]. Australia has one of the highest shares of health expenditure funded from voluntary private health insurance (PHI) premiums in the OECD, and when these are combined with OOPC, payments by individuals contribute 26 % of total health expenditure, the 12th highest among the 38 OECD member countries. OOPC vary by type of health service, from 3.6 % for public hospital services and 6.6 % for GP services, to >60 % for dental care and health aids and appliances [1].

Australia has a mixed public-private healthcare system. Its universal,

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tax-funded public insurance scheme, Medicare, functions via the Medicare Benefits Schedule (MBS) for healthcare services, and the Pharmaceutical Benefits Scheme (PBS) for medicines. Medical devices, such as insulin pumps, cochlear implants, or non-implanted prostheses are funded from a range of sources, including the MBS, some limited government programs, PHI, and individual payments. Through Medicare, Australians can access free public hospital care. For out-of-hospital (primary and referred care) the MBS includes safety nets to protect people from health-related financial burden (Table 1: Medicare Safety Net, Box 1: PBS Safety Net). Chronic disease care planning and team-based care activities are supported through Medicare's Chronic Disease Management (CDM) program [2], providing up to five subsidised consultations annually for ongoing disease monitoring and support by general practitioners (GP)s, practice nurses, allied health providers (AHP) and Aboriginal and Torres Strait Islander health workers. Additionally, people with mental health conditions can access up to ten subsidised allied health services annually through Medicare's Better Access Initiative [3]. Alongside receiving government rebates, healthcare providers can set their own fees and patients are required to pay the difference (gap payment) between the fee and the government rebate. If a provider only charges the scheduled fee, there is no gap for patients to pay, which is referred to as bulk-billing. People ≥65 years and those in receipt of welfare payments are eligible for concession cards, which enable access to lower safety net thresholds and lower payments for prescribed medications. Medicare does not cover the cost of most treatment supports, such as aids, appliances and home oxygen, although state governments may provide some support for these. Australians also have the option of purchasing private health insurance (PHI) and currently almost half of Australians are insured by PHI policies [4]. PHI mainly covers the cost of private hospital treatment, but may also cover non-Medicare subsidised services such as physiotherapy, psychology and dental services but not GP or specialist consultations. The government provides means-tested rebates for PHI. Means-tested public dental care is available to children aged 0-17 years through state and territory governments, and for adults with concession cards, however, wait lists are long and for most people, access is primarily through private dentists.

Table 1
Medicare safety net thresholds 1 January 2025 [5].

Thresholds*	Threshold amount	Who it's for	What counts towards the threshold	What benefit you'll get back after reaching the threshold
Original Medicare Safety Net (OMSN)	$576.40	Everyone in Medicare	Your gap amount for the calendar year.	100 % of the schedule fee for out of hospital services.
Extended Medicare Safety Net (EMSN)-General	$2615.50	Everyone in Medicare	Your out-of-pocket amount for the calendar year.	80 % of out-of-pocket costs or the EMSN benefit caps for out of hospital services.
Extended Medicare Safety Net (EMSN) - Concessional and Family Tax Benefit Part A	$834.50	Concession cardholders and families eligible for Family Tax Benefit Part A	Your out-of-pocket amount for the calendar year.	80 % of out-of-pocket costs or the EMSN benefits caps for out of hospital services.

*The Original Medicare Safety Net (OMSN) was introduced in 1984 to reimburse patients for the gap between the Medicare Schedule Fee and the Medicare rebate. Except for general practice consultations, patients generally receive a rebate of 85-100 % of the Schedule fee for all out-of-hospital Medicare items. The Extended Medicare Safety Net (EMSN) was introduced in 2004 to assist patients with out-of-pocket costs incurred as the difference between the MBS rebate received and the fee charged for an MBS service. There are two EMSN thresholds – one for general patients and another for concession card holders and people eligible for the Family Tax Benefit Part A. Once a person has reached the relevant EMSN threshold, in addition to the OMSN rebates, the individual or family will receive an additional rebate of 80 % of the OOPC of the service or the EMSN cap for the relevant item/s, whichever is lower. The thresholds increase annually in line with CPI increases. There were two non-CPI-index increases in 2006 and 2015. Thresholds are the same for individuals & families.

OOPC disproportionately impact people on lower incomes [6,7], young people, those with chronic illness [7] and older Australians [8]. Despite the existence of safety nets to protect people from health-related financial burden, OOPCs for out-of-hospital Medicare services are mildly regressive and those for prescription medicines, distinctly regressive; that is, people with lower incomes pay a higher proportion of their household income on healthcare and medicines [9].

Out-of-hospital healthcare costs create barriers to access at the frontlines of the health system, reducing potential benefits from prevention and early intervention [10]. People with chronic conditions tend to have lower incomes and higher healthcare costs, thus spending a greater proportion of their incomes on health care [6,8,11,12]. Individuals with multiple chronic diseases can spend up to six times the amount of those who do not have a chronic disease [11]; with those on lower incomes being 15 times more likely to incur catastrophic healthcare costs (>10 % of household income) [13].

While quantifying the high OOPC incurred by Australians with chronic conditions is essential to inform health policy, it is critical to understand the day-to-day impact of these costs on individuals and families. The existing literature is heterogeneous, exploring OOPC specific to certain conditions (e.g., cancer) [13], barriers to accessing healthcare [14], and provides varying perspectives on OOPC, from acceptable to prohibitive [14–16]. Our aim was to discover what is known about the lived experience of OOPC of out-of-hospital care by people with chronic conditions and to discuss this in relation to current Australian health policy.

2. Methods

We conducted a systematic review of the Australian qualitative literature examining people with chronic conditions' experiences of the OOPC of out-of-hospital health care and medicines in Australia. In accordance with the published protocol [17], we searched the academic literature using Pubmed, CINAHL Complete, Cochrane Library, PsycINFO and EconLit databases from 1999 to 10th April 2025. We also searched reference lists of included studies and review articles. The final search string was: ((Interview*) OR (survey*) OR (qualitative)) AND ((‘out of pocket’) OR (‘out-of-pocket’) OR (‘financial burden*’) OR (‘financial hardship*’) OR (‘health expenditure*’) OR (‘high cost*’) OR (‘financial toxicity’)) AND ((experience*) OR (perception*) OR (attitude*) OR (view*)) AND (Australia*)

Three team members (SW, AP, JD) independently reviewed studies at both title and abstract, and full-text screening stages, with conflicts resolved through consensus. Table 2 presents the inclusion and exclusion criteria. While the original search was conducted from 1999 – 2025, during data extraction, a decision was made to only include articles from 2004, when the EMSN was introduced. A data extraction template was developed and piloted by two independent reviewers (SW, JD). Risk of bias was assessed by SW, JD and AP using the Critical Appraisal Skills Programme (CASP) checklist [18]. A narrative approach was taken to data synthesis using the Centre for Reviews and Dissemination guidelines [19].

3. Results

Of 2333 studies, 37 met the inclusion criteria (Fig. 1: PRISMA

Table 2
Inclusion and exclusion criteria as described in a CHIP format.

	Inclusion criteria	Exclusion criteria
Context	Australian public health systems	-
How	Qualitative studies	-
Issues	Experiences of out-of-pocket costs	-
Populations	Adults living in Australian who have or are managing one or more chronic diseases.	-
Study design		Review articles, commentaries, letters, issue briefs, editorials, poster presentations or conference papers
Language	English	-
Setting	Australia	-
Timing	From 1 July 2004 to 1 April 2025	-

diagram). These studies provided evidence of experiences of 9/10 key chronic condition groups defined by the Australian Institute of Health and Welfare [20]: arthritis [21–23], back pain [24], cancer [13,22, 25–33], cardiovascular disease (CVD) [22,32,34], chronic obstructive pulmonary disease (COPD) [22,32], diabetes [16,22,32,35–37], chronic kidney disease (CKD) [22,38], mental health conditions [22,39,40], and osteoporosis [22,41]. In addition, included studies explored experiences of oral health [34,42], insomnia [22,43], obstructive sleep apnoea [44], spinal muscular atrophy (SMA) [45], cerebral palsy [46], and lymphoedema [46,47]. Six studies interrogated the perspectives of people living with a range of non-disease-specific chronic conditions and their carers [15,22,32,48–50]. In total, the review included the experiences of 1811 people living with chronic conditions, including carers (n=118), with ages ranging from 0 – 96 years. (see Table 3: Data extraction; Table 4: Matrix of findings by health condition; Table 5: Matrix of findings in chronological order). No previous reviews of the qualitative literature examining people with chronic conditions' experiences of the OOPC of health care and medicines were found.

Several studies purposively engaged with groups with specific demographic characteristics (see Table 6). The data collection method used most frequently was interviews [13,15,21–25,27–32,34,38–40, 43–45,47–50], followed by focus groups [16,35,42], analysis of free-text comments from surveys [26,33,41,46], deliberative workshops [16,51] and yarning circles [35].

3.1. Quality assessment

The quality of all 37 studies was considered acceptable using the CASP tool (Table S1). The question most not addressed in studies (n=14) was the relationship between the researcher and participants. However, there was no indication from the methods that any potential bias or undue influence existed in these studies. All other aspects of quality were present.

3.2. Data synthesis

Data and analysis were discussed at team meetings, where five research team members living with chronic conditions (KB, SI, JKS, JV, LW) and a Chronic Pain Clinical Nurse Consultant (FH) provided personal and professional reflections on the data; confirming similar lived experiences of OOPC. The approach to data synthesis was discussed and consensus reached. Initial themes were identified deductively using a priori categories frequently used in the literature (direct disease-attributable costs: consultations, medications, imaging and pathology, equipment and supplies, and indirect disease-attributable costs: transport, parking accommodation); additional themes were identified

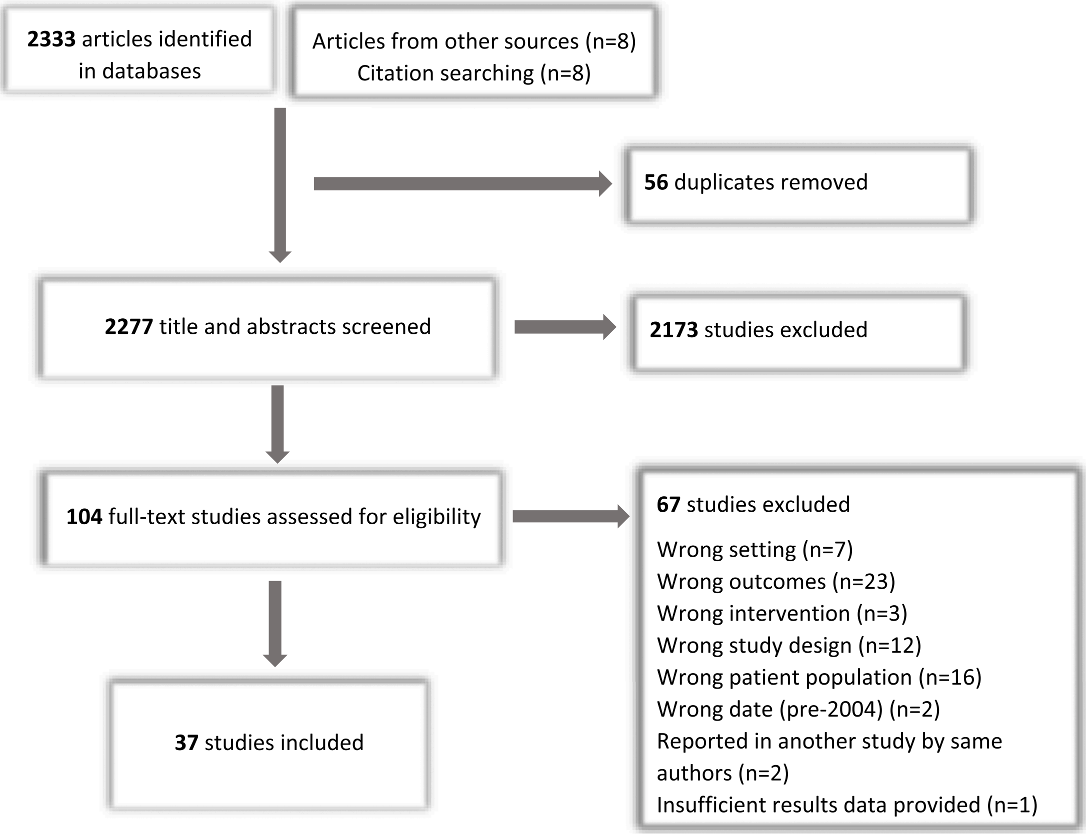

Fig. 1. PRISMA (Preferred reporting items for systematic reviews and meta-analyses) diagram.

Table 3
Data extraction.

Author	Population/ Location	N (male, female)	Aims	Methods	Consultations	Medications and equipment	Travel, Parking, accommodation	Employment/Income	Strategies/trade-offs
Berkovic 2021[17]	Adults, aged 18 – 50 years/ Urban and rural Australia wide	21 (2, 19)	To explore the perceived financial impacts of living with arthritis among younger adults (18-50 yrs.)	Semi-structured face to face interviews, 2019	Private specialist rheumatologist consultations was the greatest expenditure. No OOP costs for rheumatology appointments public hospital system. Treatment length made nonsubsidised allied health consultations expensive.	Multiple concurrent medications presented a substantial financial burden, especially to students. Medications were acknowledged as less expensive under the PBS. Financial constraints with non-medical equipment such as home ergonomic devices.	Travel was an unexpected cost as arthritis limited comfort on public transport and created health concerns if the arthritis is managed with immune modifying medications, while driving created additional costs in parking and fuel.	Reduced income and working hours due to illness and disability	Participants prioritised specialist care over allied health, with the latter sometimes stopped due to high costs. Consequences of financial burden often extended to the whole family as holidays were foregone, mortgage repayments were defaulted or extended, and children forced to enter the workplace earlier. PHI was prioritised as essential despite being one of the largest health related expenses.
Cheung 2014[40]	Adults aged 20-74 years being treated for insomnia at sleep and mental health clinics/ Urban Sydney, NSW	26 (10, 16)	To explore insomnia patient's experiences and help-seeking behaviours as they transition through self-help, primary care, and specialist care (i.e., sleep physician or psychologist specializing in sleep)	Face to face or telephone interviews, November 2011 - April 2012	The cost of attending private sleep clinics was noted and the need to have enough money to pay was noted as a key barrier to accessing treatment (RPAH clinic was free). Others included lack of local specialist services for insomnia and GPs not being well informed about referral pathways.	-	-		-
Chou 2021[41]	Adults aged 41-85 years with obstructive sleep apnoea and using CPAP/ Urban, Sydney, NSW	18(6,12)	To evaluate the treatment burden experienced by OSA patients using CPAP therapy	Face to face or telephone interviews, April - August 2019	The clinic appointment was free of charge and the burden of consultations were indirect costs including transport, parking cost, opportunity cost, waiting times and burden on carers	The OOPC burden of using CPAP was greatest despite many of the CPAP machines being subsidised by the government. For those who qualified for government subsidies, half had difficulty paying for maintenance costs and machine parts.	Travel (transport, parking, opportunity cost, waiting times, burden on carers and getting ready for healthcare appointments) was seen as a burden associated with healthcare appointments and attending them.		Some who did not receive government subsidies chose to rent CPAP machines (4/18) and others purchased them (7/18). Several participants cut back on other expenses to cope with the OOPC of the CPAP machine and to pay for gym membership to lower their risk factors for OSA. 2/18 reduced money spent on their children.
Cuesta-Briand 2014[34]	People aged 25-75+ years with type 2 diabetes from areas of high relative socioeconomic	38 (10, 28)	To explore the impact of socioeconomic disadvantage on the management of diabetes	Focus groups followed by in-depth interviews, October 2008 and March - November 2009	All participants accessed bulkbilling GPs. Cost was a barrier to accessing specialist and allied healthcare This related to both	Medication costs were not reported as a barrier. Most participants were clients of an ACCHO clinic in the sampling area and their medication was sorted in	Transport costs, including public transport fares, petrol and parking fees, were reported as a barrier to accessing healthcare services.		Participants forewent medical services due to the cost including allied health (podiatry) and specialist care (ophthalmology).

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Table 3 (*continued*)

Author	Population/ Location	N (male, female)	Aims	Methods	Consultations	Medications and equipment	Travel, Parking, accommodation	Employment/Income	Strategies/trade-offs
	disadvantage/ Urban, Perth, WA				upfront payments as well as the limited Medicare reimbursement. Participants receiving care at the Aboriginal Controlled Community Health Organisation (ACCHO) reported regular access to podiatry and some access to physiotherapists.	multi-dose medication costs at low cost and delivered to home.			Some participants reported feeling judged on the basis that they could not pay for care.
Essue 2015[49]	Community-dwelling patients aged 45-75 years enrolled in a community specialist palliative care program and their nominated family carer/ Urban, Melbourne, Victoria	Patients: 30 (17,13)	(1) To prospectively measure out-of-pocket costs of medical and health-related care, sources of financial stress and the extent of economic hardship in a sample of Australian patients with cancer at the end of life; and (2) To explore the factors that contribute to economic hardship from patients and carers' perspectives.	Mixed methods prospective study. Face to face interviews followed by 4 weekly telephone interviews until the patient's death or for 6 months, October 2010 – March 2011.	Co-payments for medical appointments were a challenge; specialist appointments were reported as highest OOPC for most.	Some reported medications as greatest financial burden. Equipment, medical supplies (e.g., incontinence pads) and home aids (e.g., lift chair), were cited as significant contributors to financial burden.	Most patients reported being unable to manage on public transport, and that private transport costs and parking presented a substantial financial burden.	The financial burden experienced was heightened by loss of income, often by the patient and carer simultaneously, due to the illness. This had immediate and long-term consequences for households, and often meant savings and/or superannuation were accessed, and homes remortgaged.	Due to cost, patients often missed medical appointments and failed to fill prescriptions. They forwent some services, such as meals on wheels and negotiated with service companies to extend payments for utilities. All participants received government assistance in the form of concession subsidies but the difficulty in accessing these subsidies were cited as an additional burden. For those receiving the subsidies, 22/30 reported economic hardship; those who did not own their homes found it especially difficult.
Farrar 2018[42]	Parents (aged 30-49 years_ of children (aged 1.6-4.1 years) with spinal muscular atrophy types II and III managed at the Sydney Children's Hospital multidisciplinary neuromuscular clinic	8 children, 7 carers (7, 0)	To gain insights into the effect caring for a child with SMA has on financial (both direct and indirect), opportunity and psychosocial costs associated with SMA care from a primary carer perspective within the Australian health system	Telephone interviews, May – June 2016	-	Most carers experienced significant costs linked to medical, seating and mobility-related equipment, such as wheelchairs and related accessibility modifications, specialised vehicles and bedding, as well as paramedical costs such as continence products and enteral formulas.	Appropriate housing was identified as the largest financial cost faced by families. For 3/7 these costs prohibited availability of wheelchair accessible housing.	6/7 mothers reported relinquishing or reducing work hours or responsibilities due to the caregiving requirements. Some mothers reported returning to work early to help pay for medical costs, while some fathers increased work hours for the same reason.	Families described delaying and prioritising certain modifications of medical equipment to save cost. Other strategies including accessing superannuation, foregoing leisure activities to redirect disposable income to fund healthcare, equipment and modifications, and weighing the costs of the affected child with the needs of other family members.

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Table 3 (*continued*)

Author	Population/ Location	N (male, female)	Aims	Methods	Consultations	Medications and equipment	Travel, Parking, accommodation	Employment/Income	Strategies/trade-offs
Frier 2021[32]	Indigenous Australians with type 2 diabetes (aged 42-67 years) and Indigenous health workers (aged 34-57)/ Rural/ remote north Queensland	7 Indigenous Australians with diabetes and 7 Indigenous Health Workers	To explore the social determinant of health (SDoH) -related barriers and facilitators to self-managing type 2 diabetes, and how these could be incorporated into the usual clinical care for Indigenous Australians with type 2 diabetes.	2 one-on-one interviews and 5 yarning circles. Only data reported by people with T2DM were utilised for the review, dates not specified		Not reported	Availability of transport, rather than cost of transport, was discussed.	Not reported	One participant reported prioritising cigarettes over insulin, while another described prioritising paying utility bills instead of attending a medical appointment.
Frier 2022[33]	Adults aged 42-79 years with type 2 diabetes mellitus (T2DM)/ Regional, rural and remote, North Queensland	10 (7, 3)	1) To explore Social Determinant of Health (SDoH) related T2DM self-management barriers and facilitators. 2) To identify and explore how to include SDoH into the usual care for individuals who have T2DM	6 interviews and 1 focus group, dates not specified.	Attendance to medical consultations was impacted by affordability of private vehicle ownership and the burden of travelling long distances via public transport.	Participants reported financial barriers to purchasing medications and affording appropriate nutrition.	Financial insecurity impacted transport options and subsequent attendance at medical appointments. It also resulted in social isolation – from both family and friends. Access to community services facilitated attendance at medical appointments and social connectedness.		Participants described prioritising the needs of family members and loved ones over their T2DM self-management.
Gulliver 2023[23]	Adults aged 26-66+ years with lived experience of cancer (at least 12 months previously)/ All areas, Australia-wide	131 (12, 119)	1) To investigate the experiences and preferences of Australian cancer survivors for health and mental healthcare; and 2) To investigate their mental health help-seeking attitudes, what has worked for them in the past to manage their mental health, and their ongoing needs to live well in the community.	An online survey collecting both quantitative and qualitative data, dates not specified	Cost was the key barrier to accessing mental healthcare for many participants. An insufficient number of subsidised appointments available under the GP CDM Plans, and the GP MHTPs. Half of participants were not aware of GP CDM Plans, whereas the majority were aware of GP MHTPs.	-	Travel distance and transport were identified as a major issue around access to physical healthcare because of the high costs involved.		One participant reported foregoing mental healthcare in order to prioritise other medical and health costs. A steady income was identified as a basic need for living well with cancer in the community.
Gunn 2022[22]	Adults aged 20-78 years who cared for a person with cancer/ Regional and rural, Australia-wide	18 (6, 12)	To explore the experiences of people caring for someone with cancer, while living in rural Australia, and the impact of the cancer-caring role on their well-being	Semi-structured telephone interviews, dates not specified			Participants reported financial, practical, and social, challenges related to travelling long distances with their loved one to access specialist medical treatment. Hidden expenses included car parking and buying meals while away.	Participants reported reducing or giving up work to care for a loved one or having to pay someone to maintain their business.	
Hendry 2013[19]	Patients aged 44-83 years with rheumatoid arthritis (RA) attending outpatient clinics in SW Sydney/ Urban, NSW	29 (5, 24)	1) To investigate whether or not foot care access is driven by foot health, disease and/or socio-demographic characteristics;	Mixed methods: Cross-sectional survey (n=29) followed by semi-structured telephone interviews	Cost was a barrier to accessing allied healthcare. Time off work to attend health consultations was	-	-	Several participants reported lost income and earning potential as a direct result of their arthritis.	Participants traded off items normally in their budget, including food, to afford foot care.

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Table 3 (*continued*)

Author	Population/ Location	N (male, female)	Aims	Methods	Consultations	Medications and equipment	Travel, Parking, accommodation	Employment/Income	Strategies/trade-offs
			2) To explore patients' perceptions of foot health services for people who have RA in Greater Western Sydney; and 3) identify perceived barriers to adequate foot care access in this region	(n=12), May 2012 – February 2013.	reported as an indirect cost.				
Henry 2023[46]	Adults and children with cerebral palsy (CP) living in Australia or their carers; (children 0–6 years (n = 47), children/ adolescents 7–17 years (n = 124) and adults (n = 100).	271 (148, 120, 3 undiscclosed)	To: 1) describe and estimate the OOPC for people with CP and their families in Australia by age and gross motor function severity; and 2) Measure experiences of financial distress experienced by these people.	Mixed methods: survey including thematic analysis of open-ended questions (n = 231)		Most costs described were related to assistive technologies such as specialised toys and equipment, including the cost of trialling prior to purchase, upgrading and repairing devices such as wheelchairs, seating, prams. Costs of service animals to assist with emotional needs. Rental costs associated with needing a bigger house for accessibility; repairs to house due to equipment and sometimes behavioural issues; Increased home contents insurance due to value of assistive technologies.	Accommodation for caregivers during hospitalisations Childcare for siblings when attending appointments	The majority of participants referred to reduced income due to their caring responsibilities, although one participant described the relief of increased income due to being able to return to work. Financial uncertainty - related to future income, changes with annual NDIS reviews, and unexpected medical costs.	Going without disability-related goods and services due to cost, including cars. People living in rental accommodation were not able to access funding for permanent home modifications. Going without leisure activities and holidays so they could pay for health-related costs. Financial assistance from family and friends. Differing comments about the NDIS – some stating great relief and support through this, others stating a lack of flexibility and gaps in support.
Hopkins 2022[21]	People aged 24-78 years accessing services for chronic non-cancer pain (CNCP)/ Urban, regional, rural; Australia-wide	26 (4, 22)	To understand how current health services providing non-pharmacological treatments are accessed by exploring the experiences of people attempting to access services.	Semi-structured telephone interviews, October 2020 – March 2021.		Use of GP CDM plans was variable, with many not aware of them. Seven participants who did use them reported needing more than five subsidised appointments. Participants with PHI reported similar issues due to ceilings on these costs.	4/6 participants in regional areas reported issues with physical availability of services, and the costs associated with travel to urban areas.	Some participants were unable to work due to pain. Loss of income added to financial stress and at times, the need to prioritise other needs over healthcare. Time off work to attend appointments imposed further financial burden.	
James 2011[75]	Patients over 18 years with lymphoedema attending an outpatient lymphoedema clinic in a metropolitan hospital/ Urban, Melbourne, Vic	8 (3,5)	1)·To identify any physical, psychosocial and/or financial factors which affect the person with lymphoedema being able to maintain an optimal skin care regime as directed by the clinic. (Two other aims not of	Semi structured face to face interviews, dates not specified	No financial issues reported	The cost of purchasing prescribed specialised skin products was a common theme.	N/A	Not reported	Patients prioritised other necessities over skin care products resulting in periods of no treatment. One participant reported using more expensive, richer products on parts of the body mostly affected and cheaper products elsewhere.

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Table 3 (*continued*)

Author	Population/ Location	N (male, female)	Aims	Methods	Consultations	Medications and equipment	Travel, Parking, accommodation	Employment/Income	Strategies/trade-offs
			relevance to this review.)						
Jeon, 2009[29]	People aged 45-85 years with, or caring for someone with, chronic heart failure, complicated diabetes and chronic obstructive pulmonary disease/ Urban, ACT and Western Sydney, NSW	52 patients (28, 24)	To examine key factors that contribute to and exacerbate economic hardship, as experienced by people affected by chronic illness	Semi structured interviews, March 2007 – January 2008.	The ability to afford frequent consultations with GPs and specialists, plus accompanying investigations added to economic hardship. Economic hardship was reported more by participants with CHF and COPD than those with diabetes.	The majority of participants who were on medication and had co-morbidities and were not in paid employment, reported economic hardship. Disease specific tools (e.g., diabetic footwear) added to financial burden. Other costs included home modifications and assistive equipment for disease management.	Some participants' conditions impacted their capacity to walk or use public transport. The cost of transportation included parking or needing to take private transport due to effects of chronic conditions impacted decision-making.	Carers discussed the financial impact of taking time off work to care for a loved one.	Choices were made between medication, food and power; one participant described foregoing medication until money was next available. Treatment costs was balanced with costs of living, and some were unable to proactively engage in behaviours to prevent further disease e.g., regular check-ups, healthy food, gym memberships. Other strategies included reliance on family, used birthday or anniversary gift vouchers, avoiding social activities, compromising on vacations, leisure activities, hobbies and home renovations,
Jeon 2012[44]	Older people (aged 53-90 years) with >3 chronic health conditions/ Urban, rural; Australia-wide	40 (17, 23)	To examine the reasons for holding PHI and the impact of maintaining PHI for older people with multiple chronic conditions	Telephone interview, March – December 2010.	Some couldn't afford annual visits to specialist due to cost. Many maintained their PHI premiums, possibly at the expense of their quality of life.	Multiple medications due to co-morbidities were a burden. Non-PBS medications were especially difficult to manage. Medical equipment was seen as big expense items and required careful forward planning.	Travel to appointments was cited as a burdensome health related cost.	Participants who worked part-time due to illness were often ineligible for government concession cards and reported financial hardship.	Participants prioritised PHI over holidays, eating out, necessities (food, petrol) with many concerned about their ability to afford basic household expenses. All participants without PHI reported juggling money to afford treatment and costs of daily living; one reported foregoing medication at times in.
Kelada, 2020[24]	Parents (aged 20-55 years) of childhood cancer survivors (median age 8.05 years)/ Urban, rural, Australia-wide	56 (6, 50)	To explore: 1. How parents of children who have completed cancer treatment describe the immediate and ongoing financial toxicity and employment disruptions as a result of their child's cancer and treatment, and 2. How parents' experiences with financial and employment impacts of	Semi-structured face and telephone interviews, dates not specified.		Out-of-pocket cost of medications after treatment completion was a major contributor to financial toxicity, especially for families living in low socioeconomic areas.	Parking fees, petrol, road tolls and other expenses related to regular travelling to treating hospitals was reported as a major source of financial toxicity.	Children's ongoing treatment needs were barriers to returning to full-time employment or re-entering the workforce. The ability to work from home, being self-employed or part-time employment enabled greater flexibility. Mothers' employment were most impacted; they often accepted lower paid roles or	Factors that protected participants from financial toxicity, included use of savings, loans, gifts from family and friends, charitable support, petrol vouchers, government welfare payments and paid leave from employment. Families from higher SES noted their income prior to the child's cancer diagnosis helped protect them from financial

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Table 3 (*continued*)

Author	Population/ Location	N (male, female)	Aims	Methods	Consultations	Medications and equipment	Travel, Parking, accommodation	Employment/Income	Strategies/trade-offs
			childhood cancer after treatment completion differ according to parent gender, family SES or family rurality?					chose part-time or casual employment or stayed at home to care for children.	toxicity post diagnosis. Lower SES families' experiences of financial toxicity varied - only five had resolved their financial toxicity related to their child's cancer treatment.
Koczwara, 2025[51]	Adult cancer survivors ($n = 19$) and multidisciplinary healthcare providers ($n = 36$) Rural/regional (33 %), urban (67 %)	Not provided	To identify the experiences and challenges some cancer survivors face in managing lymphoedema and to explore how they and healthcare professionals can best address them.	Two stakeholder consultation workshops (one online and one in-person)	High cost of specialist consultations, particularly as for many these would be lifelong.	Compression garments were expensive and participants described often choosing between managing their lymphoedema or attending to their basic needs. There were variations in government garment subsidies across states, and for some these were insufficient to meet their needs. Those with private health insurance also described the cost of compression garments as prohibitive, and PHI coverage paradoxically limited their access to government support schemes, and described navigating these payment systems as complex and overwhelming.			One participant described having to choose between buying a compression garment or buying shoes for her children.
Kunin, 2021[45]	Older individuals (>65 years; 67-96 years)) receiving home assistance through the home and community care (HACC) program/ Urban, Melbourne Vic	11 (4, 7)	To examine access-related needs and experiences of accessing primary care through the lens of the patient-centred access to care framework	Semi-structured face to face interviews, October 2017 – March 2018.	Accessing specialist care was the major health-care related expense. Participants reported an inability to pay for private healthcare and frustration with the public waitlist.	-	-		Participants managed by accepting care from family, delaying or not attending services perceived as non-urgent, including dentists and ophthalmologists, and relying on their GP to find more affordable options.
McGrath 2015[25]	Rural patients (18-70+ years) with haematological malignancies/ Rural, Queensland	45 (20, 25)	To examine the financial and psychosocial impact of relocation for specialist care	Face to face interviews, dates not specified.	Relocation for specialist care had a ripple effect, often impacting the whole family in terms of time, finances, and energy.	-	Ongoing routine and follow up care led to long hours of travel including overnight stay. This was a significant cost alongside the cost of paying for staff to look after properties during absences.		At times, the “irresolvable conflict” between attending a treatment centre and maintain a farm, led to choices between farm and treatment. Some forewent companionship from their family members who stayed back to look after the property so they

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Author	Population/ Location	N (male, female)	Aims	Methods	Consultations	Medications and equipment	Travel, Parking, accommodation	Employment/Income	Strategies/trade-offs
									could save on paying for staff to perform that role.
McGrath, 2016[26]	Rural patients (18-70+ years) with haematological malignancies/ Rural, Queensland	45 (20, 25)	To explore the gaps in understanding OOP costs for cancer patients travelling to treatment centres.	Telephone interviews, dates not specified.	-	Medications costs included follow up treatment drugs post hospital discharge, symptom relief, immunosuppressant drugs, steroids and maintenance drugs. The cost was especially pronounced if participants did not have a healthcare card or following reset of the PBS safety threshold.	The Patient Assisted Travel Scheme (PATS) was considered helpful but did not cover all OOPC of travel and accommodation of the carer and return trips home during treatment. Other costs included emergency flights, fares to and from the departure airport, costs with administrative problems, tolls and fines, public transport, taxi and food due to double grocery bills, lack of familiarity with locations of less expensive food.		In order to pay OOPC of health, some chose to substitute certain necessities (e.g., saved on mobile phone costs by using skype or Facebook).
McMillan, 2020[36]	Young people (14 – 25 years) who had used a prescription medication for any mental illness for a minimum of 2 months/ Urban, Brisbane, Qld	18(2,16)	To explore the experiences of young Australians taking and managing medication for any mental illness.	Face to face interviews, October 2017–September 2018	-	Medication costs were considered “exorbitant” in this population of young people with limited financial resources due to study, part-time work and at times, being too unwell to work. Trialling medications was seen as costly and a waste of money.			Parents assisted with some medications which was appreciated by some participants and led to guilt in others, which sometimes resulted in delayed use and worsening symptoms. One participant described choosing between paying for medication and paying rent. Medication sharing between household members was used sometimes to circumvent expenses associated with trialling medications.
Medway, 2015[35]	Carers (aged 20-60 years) of children (aged 6-18 years) with chronic kidney disease (CKD)/ Urban, rural, NSW and Queensland	27 (5, 22)	To describe the experiences, perspectives, and beliefs of parents caring for children on the financial impact of CKD.	Semi-structured face to face interviews, April – September 2013.	-	For some, a lack of reimbursement for items such as supplements, syringes, disinfectant, significantly added to the family’s expenditure.	For families located outside metropolitan areas, travel costs were substantial, including petrol, food, parking, and car maintenance. Some participants used public transport to go to the hospital to reduce costs, despite this being more difficult and time consuming than driving. One family needed commercial flights to and from the hospital.	Some participants took leave without pay or were unable to work. Employment options, including self-employment were significantly limited. Balancing home peritoneal dialysis with home-based paid work was found to be unsustainable. Mothers often reduced work, while fathers increased work	Some chose to use public transport to reduce travel costs but it was seen as more time consuming and difficult than private travel. Other saving strategies included buying in bulk, buying from less expensive sources, being cautious with spending on necessities (groceries, clothing), being on a payment plan, re-channelling resources to

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Author	Population/ Location	N (male, female)	Aims	Methods	Consultations	Medications and equipment	Travel, Parking, accommodation	Employment/Income	Strategies/trade-offs
								responsibilities to cover costs. Participants with higher household incomes reported having more choices and resources.	basic needs (from mortgage repayments), imposition of debt, seeking help from family, minimising social activities (dining out, holidays, extracurricular activities for other family members).
Newton 2020[53]	Cancer patients aged 18 years and over (breast, lung, prostate, colorectal)/ Urban, rural, Western Australia	40(22,18)	To explore the complex narratives of cancer patients undergoing treatment and the impact of OOPC on their experience to gain an insight into their subjective and objective experiences of financial toxicity	Semi-structured face to face interviews, 2016 - 2017.	Being told the cost of consultations upfront was helpful, although one participant reported being too embarrassed to ask how much imaging and pathology OOPC would be. Treatment and investigation costs were sometimes unexpected and for some, not covered by PHI. The cost of private imaging was not fully covered for those with PHI and those without PHI reported high OOPC after the Medicare rebate.	Some reported expenses to manage side effects and complications of medications. Some were stuck using their current regimens despite side effects, as their finances restricted them from trialling other medications. Uncertainty related to length and the type of medications used which impacted financial planning.	Indirect costs related to transport included use of private driving due to effects of their treatment (e.g., immunodeficiency). Of transport costs, hospital parking fees were considered significant. Most received help for travel and accommodation services through NGOs and the PATS.	Half of participants continued to work after diagnosis. Those with access to leave and supportive employers were less affected by OOPC. Self-employed participants reported challenges with loss of income due to treatment. Five participants lost their jobs due to treatment or side-effects. Some retired participants struggled with OOPC despite access to subsidies.	Some chose to use suboptimal amounts of medications due to cost. Other strategies included using savings, superannuation, obtaining a credit card to pay costs upfront, relying on family to take them to appointments, using available subsidies and strict budgeting. Trade-offs included withholding against necessities (e.g., heating during winter to reduce electricity bills).
Omonaiye 2025[37]	Adults with T2DM (Vietnamese country of birth and/or language spo- ken at home) and focus group discussions with health providers involved in the care of people with T2DM from Vietnamese background.	23 (9,14)	To explore factors influencing diabetes medication-taking among adults of Vietnamese heritage with type 2 diabetes mellitus (T2DM) residing in Australia.	Interviews with adults with T2DM and one focus group with healthcare providers.		Access to subsidized medications via the Pharmaceutical Benefits Scheme (PBS) was described as an enabler for taking medications as prescribed by some participants: For others, the high costs of medication prevented them from complying with the prescribed regimen, with one participant stating they only took half the prescribed amount to make it last longer.			
Parker 2021[27]	Patients (40-69 years years) in remission from acute myeloid leukemia (AML)/ Urban, Melbourne, Vic	11 (8,3)	To explore the perceived financial impact of AML, a rare haematological malignancy, where patients may be particularly vulnerable to financial stress due to	Semi structured face to face interviews, dates not specified.	-	The cost of medication post-hospital stay was reported as expensive and a source of stress.	Travel costs (parking, petrol) were most burdensome during the acute treatment period, with some citing parking as their biggest cost.	Loss of or reduction in employment due to initial length of treatment and ongoing ill-health. The associated financial strain was substantial,	Strategies to manage finances included tight budgeting, reduced social activities (eating out, postponing leisure travel), use of savings, early access to retirement funds,

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Author	**Population/ Location**	N (male, female)	**Aims**	**Methods**	**Consultations**	**Medications and equipment**	**Travel, Parking, accommodation**	**Employment/Income**	**Strategies/trade-offs**
			the lengthy, specialised and centralised care					with some building large amounts of debt.	accumulating debt, change of working pattern (choosing to be less risky in business), seeing financial advisors. Notably, one individual prioritised leisure travel due to the serious nature of their illness. Some required paying for extra home help due to reduced physical functioning and was exacerbated by their length treatment regime and hospital stay which restricted their ability to work.
Sanchez 2017[31]	Patients (39-78 years) with cardiovascular disease (CVD) attending cardiac rehabilitation at three metropolitan hospitals in Sydney/ Urban, Sydney, NSW	12(10, 2) Mean age 60.33 years	To explore the perception of patients with CVD towards oral health and the potential for cardiac care clinicians to promote oral health.	Face to face interviews, December 2015 – January 2016.	Cost was identified as a major barrier to accessing healthcare consultations for most with some unable to justify the cost. Receiving financial support, having PHI, or support such as transport assisted people to access dental care.	-	Lack of ability to travel affected access to dental care. The cost of transport was not mentioned.		Decisions included relying on family members for transport or accessing a state concession card for transport and choosing to go through the public dental service.
Sav 2013[18]	People aged over 18 years with chronic conditions or an unpaid carer of someone with chronic conditions/ Urban, rural, Australia-wide	97 (32, 65)	To comprehensively exploring treatment burden among people with a variety of chronic conditions and comorbidities, and from various backgrounds, and their carers.	Semi structured face to face interviews, May – October 2012.	Financial burden related to consultations and medications was the most widely discussed burden.	Medications and health consultations were the major OOP cost for most. The cost was exacerbated when there was need to trial medications. It was also complicated by generic and original brand medications, especially for the elderly. Some insisted on purchasing original brand medications, further adding to their financial burden.	Travel costs and burden were most evident for those in rural and remote areas, who often travelled 3-4 h each way. Travel costs were exacerbated by the number of appointments needed.	Participants in full-time employment reported lost income due to illness and an inability to qualify for government concessions, which added financial burden.	Economically disadvantaged participants prioritised medications in terms of cost and capacity to pay. Non-PBS subsidised medications were not always purchased. Medication needs were often prioritised over the social and recreational needs of other children, and for some, taking suboptimal treatment regimens. For some living in remote and rural locations, it was untenable to travel long hours leading to decisions to relocate. Financial burden of treatment led to reliance on savings, superannuation, and family, particularly for

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Author	Population/ Location	N (male, female)	Aims	Methods	Consultations	Medications and equipment	Travel, Parking, accommodation	Employment/Income	Strategies/trade-offs
									retirees. While the cost of PHI was a burden itself, for many it was seen as a partial solution. Those without PHI were concerned about treatment waiting times.
Savaglio, 2023[37]	Young people (10-25 years) with lived experience of mental illness in Tasmania, and carers of young people with mental illness/ Urban Tasmania	61 (43, 14, 2 non-binary)	To explore young people' and their carers' experiences of mental health services, focusing on the barriers and facilitators to supporting their psychosocial functioning.	Semi-structured one-on-one or dyad interview (carer and child together), 2022	Young participants identified consultation costs and lack of access to bulkbilling as barriers to accessing psychological support. At the same time, a carer identified that being able to afford to pay for private services enabled access. All young people and carers identified that long waiting lists for services prevented or delayed engagement with supports.	-	Young people reported difficulties accessing services due to the location, distance and amount of travel required to attend; however, it was time, rather than cost, that was the burden.	-	-
Scholes-Robertson 2023[47]	Caregivers of adult (over 18 years) rural patientswith chronic kidney disease (CKD) treated with dialysis or kidney transplantation/ Rural; Australia-wide.	18 (5,13))	To identify the challenges faced by caregivers of patients with chronic kidney disease from rural Australian communities; to inform strategies to overcome these challenges	Semi-structured interviews conducted face-to-face, over the phone, or by videoconference, July 2020 – October 2021.	Caregivers reported an inability to afford the OOPC of specialist consultations. One participant reported a cardiology consultation costing $400 per visit, and this consultation was needed every three months. Even after the Medicare rebate, the OOPC were too much. Social workers attempted to have the cost reduced.	The financial burden of medications, added to the cost of consultations and travel, was substantial.	Transport was an ongoing financial and logistical hurdle for caregivers, particularly when the patient was not able to drive long distances or was unable to take public transport independently. They were concerned at the lack of resources and funding available for patient transportation.	Participants reported taking a lot of time off work or being unable to return to work due to concern for their family member's physical and emotional wellbeing. Some appreciated the willingness of their employers to be flexible and supportive when they had to attend the hospital with patients, which in one case was six times in two months.	Participants expressed concerns about the financial and emotional impact on other children in the family.
Skrabal Ross 2021[28]	Adult (20-78 years) cancer patients/ survivors/ Rural – remote, Australia-wide	20(6, 14)	To know more about the unique experiences and cost saving strategies employed by at risk rural cancer patients and survivors with the intention to informing the development of tailored tools to help reduce the impact of financial toxicity among rural people affected by cancer.	Semi structured phone interviews, dates not specified.	Travel costs to attend specialist consultations were the key financial burden in this study.	Participants without partners felt particularly disadvantaged due to not having a partner's income to offset costs, including inability to work due to illness.	Travel costs were exacerbated by length of treatment, and accompaniment by family members.		Cost saving strategies included selling personal items, buying cheaper food and reducing dining out, accessing savings and superannuation, reducing or missing holidays, avoiding or reducing entertainment and social activities, negotiating payment for utilities sometimes at the expense of emotional

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Author	Population/ Location	N (male, female)	Aims	Methods	Consultations	Medications and equipment	Travel, Parking, accommodation	Employment/Income	Strategies/trade-offs
									wellbeing, staying with friends and families during treatment in metropolitan areas (reduces effort needed to travel and is cost saving), Borrowing money from family, reducing fuel use, accessing government subsidised travel schemes).
Slavova-Azmanova 2020[30]	Adults (over 18 years) diagnosed with breast, prostate, colorectal or lung cancer/ Rural/ remote (30 %), outer metorpolitan (70 %)	26 (4, 22) median age of 66 years (IQR: 58-71)	To identify patients' perceptions of cancer-related costs.	Content analysis of free-text comments provided in a survey related to the costs of treatment and its impact, April 2014 – April 2017.	Participants seeing private specialists reported high OOPC, reported by some to be "over and above the recommended fee". Many rural participants reported providers waiving gap payments. Some participants accessed care in the public regional hospital, including access to telehealth. Some participants chose not to attend Allied Health consultations due to cost. Some participants with PHI reported minimal OOPC, although others felt that while it gave them choice, they also reported high gap payments for specialists, pathology and imaging.	Many expressed concern about the OOPC of medications, follow-up appointments and investigations.	The cost of accessing treatment in urban centres included travel, fuel, parking and accommodation. Rural participants noted that specialists did not always consider distance and travel when booking appointments. One described an additional plane trip due to mismatched appointment days.	Employed participants emphasized the importance of leave (sick leave, long service leave, ability to work). Some reported their treatment/illness leading changing work duties, reducing work hours, early retirement, job loss, and struggling to find employment.	Due to travel needs, some refused radiotherapy as they could not be away from families for the duration of the treatment. The length of time also means that some use up all their annual leave and long service leave entitlements for treatment. One person chose to have their treatment at a private radiation therapy provider because the distance to the public tertiary hospital would mean the parking and petrol would cost nearly as much as the private facility. General strategies to manage OOPC included using savings, superannuation, or credit cards; receiving financial help from families; income protection, life and trauma insurance; receiving support from NGOs and the community (Cancer Council, Solaris Cancer Care) in the form of accommodation, food cards, fuel vouchers, and free house cleaning services.
Song, 2019[46]	People (29-88 years) living with ≥1 chronic condition and their carers, and primary	20 (5, 15) 18 patients & 2 carers	To understand the perspectives of people living with chronic conditions, their carers,	Semi-structured interviews, face-to-face or via telephone,	Many participants had a regular GP who provided some form of bulk billing. This			One carer described the loss of dual incomes due to her husband's illness and	-

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Author	Population/ Location	N (male, female)	Aims	Methods	Consultations	Medications and equipment	Travel, Parking, accommodation	Employment/Income	Strategies/trade-offs
	care providers/ Urban - remote, NSW		and primary care providers about aspects of their experience, particularly in relation to accessing Australian general practice.	October 2016 - October 2017.	varied between practices and providers, with most bulk billing based on perceived needs, identified as concession card holders or patients selected at providers' discretion. Some practices had specific time periods reserved for bulk billing. Illness factors, rather than cost, were identified as barriers to attending consultations, including disability, fatigue, and pain.			the need for her to give up work to care for him. Financial strain was a barrier to paying OOPC for GP consultations.	
Sutton 2023[50]	People aged 45 years and over, with OA/ Urban and rural, Tasmania	26 (5, 21) Mean age 66 years.	To: (1) explore the experience of people living with OA, (2) gain an understanding of their navigation of the health system and, (3) explore their opinions on the role of exercise and joint replacement surgery for the management of OA	Semi-structured interviews, April – December 2019.	Some participants referred to cost as a consideration when pursuing Allied Health treatments, such as physiotherapy or movement programs. Other participants described opting out of physiotherapy due to cost and later becoming aware of available rebates available via GP CDM Plans.				
Tynan, 2022[39]	Aboriginal and Torres Strait Islanders peoples (adults aged 18-50+ years)/ Rural, Queensland	27 (10, 17)	To explore the experience of engaging in oral healthcare and prevention in a rural Aboriginal and Torres Strait Islander community and the implications this has on treatment seeking and preventative behaviour.	Focus groups and in-depth interviews (total 15), dates not specified.	The cost of private dental care was a direct barrier to access and waiting lists to attend public dentist were very long, sometime years long.	The cost of oral hygiene products, such a toothbrushes and toothpaste, and of health food, were barriers to preventive care.	Lack of access to private or public transport was a key barrier to accessing oral health services. The local community bus for travel to health appointments was limited by seat numbers, inflexible schedules, and exclusion of children.	Costs associated with taking time off work to attend the dentist for individuals and others were a barrier to prevention and treatment.	Chose not to re-attend consultations, self-managed by asking other community members to pull out teeth, delaying treatment, attending the ED at the local hospital, requesting family for help with transport, juggling medical and utility bills.
Walkom 2013[38]	Women in three age cohorts (1973-78; 1946-51; 1921-26)/ Urban – remote, Australia-wide	319 women	To elucidate women's experiences with the day to day expenses that relate to medicines and their healthcare.	Content analysis of free-text comments in the Australian Longitudinal Study on Women's Health Survey	Women from all age cohorts raised concerns with the reduction or lack of bulk billing medical services in their areas. Some participants expressed feeling of embarrassment over their financial positions and avoiding care seeking due to this.	1946-51 cohort: mentioned the on-going cost of medications for chronic illnesses. 1921-26 cohort: the high cost of medicines in general was an issue for both self-funded retirees and for women receiving a pension in the. Some self-funded retirees were unhappy that their income precluded	Rural participants reported high costs related to travel and accommodation when seeking specialist care.		One participant reported weighing up the cost of a GP consultation and medication. While the consultation is necessary to obtain the prescription, the OOPC of the consultation precluded subsequent filling of the prescription.

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Author	Population/ Location	N (male, female)	Aims	Methods	Consultations	Medications and equipment	Travel, Parking, accommodation	Employment/Income	Strategies/trade-offs
					Some participants perceived that high quality primary care was not bulk billed.	them from receiving a healthcare concession card. Women in both these cohorts: the high cost of non-subsidised osteoporosis medications as a barrier to use.			
Whitty, 2014[13]	People (aged 60-83 years) with a chronic condition or who cared for someone with a chronic condition/ Urban and rural	97 (32, 65) 70 are with chronic condtiions; 8 carers; 19 consumers and carers	To explore the perceptions of Australian consumers and carers of the financial burden associated with the use of medicines for the treatment of chronic conditions.	Semi structured face to face or telephone interviews (n=97, May – October 2012.	-	Financial burden of medications was described as having the greatest impact of medical conditions. Having to take more than one medication and the long-term nature of health conditions added to the burden. Variation in cost of medicines between pharmacies was considered inappropriate. The cost of aids such as Webster Packs added to financial burden.	-	Participants reported having to cease employment due to ill health, which aggravated the financial strain.	Medical nonadherence (especially for non-PBS subsidised items), forgoing luxury items (alcohol, cigarettes, chocolate), stocking up on medications prior to the reset of the PBS safety net, choosing doctors who provided free medicine samples. One participant reporting decreasing work hours to ensure they were eligible for a concession card.

inductively during data analysis (employment, housing, PHI, strategies used to manage OOPC, and choices and trade-offs).

3.3. Direct disease-associated costs

Consultations: Challenges in affording the upfront and OOPC of consultation fees for GPs [21,23,41,49], non-GP specialists (henceforth referred to as specialists) [16,21,23,28,32,33,43,48,50,52,53], and AHPs [16,21,23,24,26,33,40,54] were discussed in 17 studies. Participants in four studies from 2004–2019 described challenges affording GP copayments [21,23,41,49]; some stated they could not afford to consult any doctor if they were not bulk-billed [41]. While many were able to access bulk billing GPs [49], some expressed concern with the reduction in availability of bulk-billing services [21], particularly in rural areas [41].

The cost of private specialist consultations was reported as a major barrier to receiving care in 12 studies [16,21,23,28,32,33,38,43,48,50,52,53] spanning the full review period, including for people with osteoarthritis [21], type 2 diabetes mellitis (T2DM) [16], insomnia [43], rural patients with CKD [52] and older people [48,50]; many reported being unable to attend visits due to this [16,48,50]. Specialist consultations provided at public hospital outpatient clinics are free, and some people with osteoarthritis [21], rheumatoid arthritis [23], cancer [33] and obstructive sleep apnoea [44] received care with no OOPC in this setting. However, long waiting times were reported for such services, leading people to seek care from private specialists. Adults with cancer reported OOPC for private specialist consultations well above the recommended fee; however, many rural patients reported private urban providers waiving gap payments [33].

Participants in eight studies [16,21,23,24,26,33,36,40,54] from 2013 to 2023 reported cost as a barrier to accessing AHPs. Participants in three studies expressed the need for more than five subsidised AHP consultations, through the GP CDM plans, to meet their treatment needs [21,24,26]. Cost was also a barrier to seeking psychological support for young people living with mental illness [40] and people with cancer [26]. People with chronic non-cancer pain [24], osteoarthritis [54], and cancer [26] reported being unaware of the availability of CDM plans to subsidise the cost of allied health care. Many who were aware of them could not afford the gap payments, including people with arthritis [21,23,54], cancer [33], and T1DM [16]. People receiving care at an Aboriginal Community Controlled Health Organisation (ACCHO) had access to no-cost podiatry and some physiotherapy services [16].

Cost was the main barrier to accessing dental care for people receiving end-of-life care [53], some older women [41], Indigenous people [42], and people with CVD [34]. Waitlists for public dental care were described by some Indigenous people as “years long” [42]. Some people with cardiovascular disease had not seen a dentist for more than seven years and one for 20 years [34].

Medications: Participants in 19 studies spanning the review period reported challenges in affording medications [15,21–23,27,29,30,32,33,36,37–39,41,45,47,50]. For people taking multiple medications due to comorbidity, the cost burden was prominent [15,32,50,55] and described by some as having the greatest impact [15,55]. Non-PBS subsidised medications were especially difficult to afford for people with multimorbidity [22,50], and a barrier to use [50,56].

In one study, the majority were not in paid employment and reported substantial economic hardship [32]; however, Indigenous participants in this study reported less concern with costs due to the Closing the Gap Policy, which they reported had made a big difference to their lives [55]. The cost of medications was considered “exorbitant” for young people living with mental illness, exacerbated when there was a need to trial new medications [55], which some considered a waste of money [39]. Medication cost was an issue for both women receiving a pension and self-funded retirees, some of whose incomes precluded them from receiving concession cards [56]. The cost of specialised skin products for lymphoedema was described as “prohibitive”[47]. The OOPC of medications post-hospital treatment for cancer was a major contributor to financial toxicity [27] and a source of stress [57], and people receiving end-of-life care described it as the greatest financial burden [53]. For people with haematological malignancies, the cost of medications was especially pronounced for those without concession cards or following reset of the PBS safety threshold [29]. Some people with arthritis [21] and T2DM [37] acknowledged the relief PBS provided, although others, particularly low-income earners with T2DM [37] arthritis [21] and people receiving end-of-life care [53] reported struggling with medication costs before reaching the PBS safety net [15].

Equipment and supplies: The cost of necessary equipment and supplies contributed to financial burden [45,46,53] and was often described as unaffordable [21,38,44,50]. Even if a device was subsidised or paid for (e.g., continuous positive airway pressure (CPAP) device [44]) the cost of supplies, required parts and maintenance was often unaffordable [32,44]. These included ergonomic devices for people with arthritis [21], aids and incontinence pads for end-of-life care [53], wheelchairs, specialised bedding, continence pads and enteral formulas for young people with spinal muscular atrophy (SMA) [45] and people with cerebral palsy [46], diabetic footwear [32], supplements and syringes [38]. For some Indigenous people, the cost of oral hygiene products such as toothbrushes and toothpaste were barriers to preventive care [42].

Transport and associated costs: The burdensome cost of transport and parking to attend appointments were described in 24 studies across the full review period, including for people living in urban, regional, rural, and remote areas [13,16,21,22,24–33,36,38,40–42,44,50,53]. Transport costs were a barrier to attending medical appointments for people in urban areas living with T2DM [16], mental illness [40], and in remission from AML [57]; cost was often increased due to need to use private transport due to ill-health and associated parking fees [21,32,53]. People living with cancer in Tasmania described the cost of transport as a major barrier to accessing consultations [26]. For people living outside urban areas, the cost of travel to access treatments were high [22,24,25,28,29,31,33,36,38,52,58] and some were required to pay others to look after properties during absences [28]. The need for accommodation added to the financial burden [24,27–29,33,38,41,46]. and the for those not well enough to drive long distances or take public transport independently, the need to be accompanied by a family member [22,25,28,31,38,52] compounded costs.

Parking costs were specifically mentioned in 11 studies, half of which were based in urban areas [16,32,44,53,57] and half in both urban and rural areas [21,25,27,33,38,58]. For many this was to access specialist care at public outpatient clinics. For people with cancer [58] and in remission from AML [57] hospital parking fees were described as their greatest cost during the acute phase of illness.

3.4. Indirect disease-attributable costs

Employment: The financial impact of reducing employment (due to being unwell or to care for family members) impacted individuals with chronic conditions [13,15,21–25,28,30,31,33,42,46,50], their parents [27,38,45,46] and other family members [25,27,33,38,45,49]. For many people with cancer, loss or reduction of employment due to both the initial length of treatment and ongoing ill-health placed a substantial strain on finances [33,57]. Some people described job loss, struggling to find employment [33] and accruing large amounts of debt [57]. In one study, five participants lost their jobs due to treatment or side-effects, whereas those with access to leave and with supportive employers were less affected by OOPC [58]. Self-employed individuals reported particular challenges of juggling health and work [58]. Some people receiving end-of-life care described immediate and long-term consequences of lost income, often by the patient and carer simultaneously [53]. Parents of childhood cancer survivors [27] and children with CKD [38], and carers of people with cerebral palsy [46] reported treatment needs leading to an inability to work and taking leave without pay [38] and as barriers to re-entering the workforce [27]. An ability to work from home, being self-employed or part-time employment enabled greater flexibility [27], although carers of children with CKD found the balance between home peritoneal dialysis and home-based work unsustainable [38]. Returning to work after a child received a transplant was often difficult due to the length of time away from the workforce [38]. Families with higher incomes reported having more choices and resources [27,38].

Housing: People receiving end-of-life care who remortgaged their homes due to reduced income and those who rented found it especially difficult to live off Government pensions [53]. People with cerebral palsy and carers living in rental properties described being unable to access funding for permanent home modifications as well as the higher cost of larger houses to enable accessibility. Other ongoing costs included increased home contents insurance due to the value of assistive technologies [46]. Appropriate housing was identified as the largest financial cost faced by families of children with SMA; for almost half, cost was prohibitive to the availability of wheelchair-accessible housing [45].

3.5. Private health insurance

For many people, PHI alleviated the financial burden and was considered essential for health management [21,22,24,27,33,50]; however, others described it as a financial burden in itself and a significant source of OOPC [21,22,33,50]. People receiving end-of-life care felt PHI provided some relief but did not fully buffer the economic burden for ancillary care and medical tests, and some struggled to pay upfront costs incurred alongside PHI [53]. Some people with various chronic health conditions described a sense of security in having PHI [50], while some saw it as a partial solution in terms of public waitlists [22] despite this, they described feeling the pressure of increasing premiums and large OOPC of health services [22,50]. People with chronic non-cancer pain described inadequate Medicare cover for physiotherapy treatment and those with PHI described similar experiences with PHI annual ceilings that provided cover for short periods of time [24]. People required to use compression garments to manage lymphoedema described PHI limiting their access to government support schemes [51].

Three studies purposively recruited people from CALD backgrounds [37] or in addition to other participants [15,22], although OOPC experiences related to this population were undifferentiated from others. Six studies purposively recruited Aboriginal and Torres Strait Islander people alone [15,35,42] or in addition to other participants [16,22,32]. Participants in two studies reported access to care was freely available via Aboriginal Controlled Community Health Organisations (ACCHO) [32] and the Closing the Gap Policy [22], however no difference was noted between Aboriginal and Torres Strait Islander and non-Indigenous participants in the remaining study [16].

3.6. Strategies used to manage OOPC

Consultations: People receiving end-of-life care reported not attending GP consultations due to cost [53] and participants in studies about various chronic conditions reported attending at specified times when consultations would be bulk-billed [49] or avoided seeking care due to embarrassment over their financial positions [41,50]. One participant reported weighing up the cost of a GP consultation and medication; while the consultation was necessary to obtain the prescription, the OOPC of the consultation precluded subsequent purchase of the medication [41].

The choice to not see a specialist was reported by people receiving end-of-life care [53], and older Australians with one or more conditions (cardiologist) [50] and a low income earner with diabetes (ophthalmologist) [16]. Some people with arthritis reported choosing between specialists [21] and prioritising specialists over allied health care [21]. Cancer survivors described foregoing mental health care to prioritise other cancer-related medical and health costs [26], and older people reported delaying or not attending services perceived as non-urgent, including dentists and ophthalmologists, and relying on their GP to find more affordable options [48].

People with arthritis reported not attending physiotherapy due to cost [21,54] and low income earners reported not attending podiatry for diabetes care [16]. Due to cost, people in living in rural and outer metropolitan areas of Western Australia often did not attend allied health services at all [33], and some people living with chronic pain stopped attending allied health appointments after using the five CDM plan subsidised appointments [24]. Young people with cancer [26] and mental health conditions [40] reported not accessing psychological support under the Better Access program due to cost.

People with cardiovascular disease reported not seeing a dentist at all or waiting until they got a toothache [34]. Indigenous people in rural areas often chose not to re-attend consultations, self-managed by asking other community members to pull out teeth, or delayed treatment; receiving financial support, having PHI, or transport support (state concession card) assisted some to access dental care [34].

Medications: Choices between medication and household needs were reported by people receiving end-of-life care [53] various chronic conditions [55], and young people living with mental illness [39]. These choices included food and household bills [53], the social and recreational needs of other children [22], and rent [39]. Some people with cancer continued to use their current regimens despite side effects, as their finances restricted them from trialling other medications [58]. The financial burden of treatment led to reliance on savings, superannuation, and family, particularly for retirees [55].

Strategies used to manage cost included altering doses [13], substituting medications [15], not taking them at all [39,50,53], (especially Non-PBS subsidised medications [22]) or using alternative treatments [41]. Young people living with mental illness shared medications between household members to circumvent the costs of trialling medications [39]. In studies about people with type 2 diabetes, one participant reported prioritising cigarettes over insulin [35] and others prioritised the needs of loved ones over self-management [36]. Some people with arthritis stocked up on medications at the end of the year, prior to the PBS reset [15]. Non-PBS subsidised medications were not always purchased [15,55].

Equipment and supplies: Carers of children with SMA described accessing superannuation early, delaying and prioritising certain modifications of medical equipment to save cost for equipment and supplies [45]. People with obstructive sleep apnoea cut back on other expenses to afford the cost of buying or renting CPAP machines, including reducing money spent on their children [44].

Transport and associated costs: The Patient Assisted Travel Scheme (PATS) was considered helpful for most people who accessed it [25,31,33,38,58], although people with cancer and their carers described the system and paperwork as difficult to navigate [25,58], and reported long wait times for remuneration [33]. Some carers of children with CKD reported subsidies to be inadequate [38], as did people with cancer living on low incomes [58]. Some of the former (CKD) chose to use public transport to reduce travel costs but it was seen as more time consuming and difficult than private travel [38]. For some people with various chronic conditions living in remote and rural locations, it was untenable to travel long hours, leading to decisions to relocate [55]. Cost saving strategies for adult cancer survivors included accessing savings and superannuation, staying with friends and families during treatment in metropolitan areas, travelling alone to enable a carer to maintain work income and borrowing money from family [31].

Employment: Some people living with cancer described changing work duties, reducing hours, retiring early, struggling to find employment, and job loss [33]. Mothers of childhood cancer survivors reported accepting lower paid roles, choosing part-time or casual employment or becoming stay-at-home mothers to care for children [27]. Conversely, some mothers caring for children with SMA returned to work early to help pay for medical costs [45], and in two studies, fathers increased work hours for the same reason [38,45]. For people who were able to remain employed during their cancer journey, the importance of sick leave, long service leave, and the ability to work were emphasised [33]; however for some, taking time off to attend appointments for themselves [23,24,38,42] and others [38,52] added to the financial burden. Flexible and supportive employers were appreciated by people with CKD who had to attend appointments with family members [52]. Some retired people with cancer struggled with OOPC despite access to Medicare and PBS subsidies [58]. Ineligibility for government concession cards added to financial hardship for older people with multimorbidity who worked part-time due to illness [50] and people with various chronic conditions, including cerebral palsy [46], and their unpaid carers who reported lost income due to illness [55]. One person reported decreasing work hours to ensure they were eligible for a concession card [15].

Housing: Carers of children with SMA reported strategies to afford the cost of necessary home modifications, including doing it themselves or delaying or carrying out the least possible modifications [45].

Private Health Insurance: Sacrifices made to afford PHI included prioritizing it over holidays, social outings, and necessities such as food and petrol [22,50], and family holidays [21], with many concerned about their ability to afford basic household expenses [50]. In one study of elderly people, two participants had sold their homes in order to afford PHI and one participant who could no longer afford PHI chose not to visit the doctor due to a sense of shame in relying on the government [50]. Some people with arthritis who could not afford PHI felt frustrated that those who could were able to access both public and private health systems, potentially adding to the burden for others who could not afford PHI [21].

3.7. *Choices and trade-offs*

The data described shared experiences of balancing priorities due to financial constraints and making trade-offs between receiving optimal healthcare and foregoing necessities such as food [22,31,36,41,50,53], (particularly for people managing diabetes [22,36]) and certain proportions of medical care [16,21,23,24,26,33,50,53]. The choice between food and health care (most often medication) was raised in six studies [23,31,32,38,41], including the subsequent need to seek food from charities [38].

With the aim to sustain their and their families' lives, greatly impacted by the need to manage their health, people described reconsidering everyday expenses and rechannelling finances [15,30,31,38,45]. This often resulted in foregone family holidays [30,31,38,45,46,50], extracurricular activities for children [21,22,38,45], or in extreme situations, selling properties and relocating to be closer to health services.[30,50]Five studies described people juggling utilities and health costs, including paying utility bills instead of attending medical appointments [35], withholding heating in winter to reduce power bills [58], friends and family paying utility bills [42,52], and negotiating with service companies to extend payments. It was clear that as a result of these trade-offs people experienced significant loss of social connectedness [22,25,27,30,31,38,45,50] and self-worth [27,30,38,45].

While some people described the value of government subsidies [15,21,22,27,30,31,38,45] in enabling them to manage their health, others found it necessary to use their savings [13,22,27,30,31,33,38,50], superannuation [30,31,36] and credit cards [30,33,38]. Other than support provided through government subsidies, financial support was provided by families [21,22,27,28,31,33,38,39,44,46,48], charities [27,33,45] and non-government organisations or community groups[31,33]. It is important to note that despite the overall financial insecurity described by people living with chronic conditions in this review, some studies reported individuals experiencing no OOP challenges, largely due to their favourable financial circumstances [27,33,38] or a more comprehensive coverage of healthcare expenses they were able to receive from pensions and other benefit schemes [13,15,30,33,34,38], or PHI [13,50].

4. Discussion

Our analysis indicates that people with chronic conditions are presented with a treatment plan that includes a package of items that are required to manage their health; this may include various healthcare consultations and associated follow-up, medications, equipment and/or supplies, and home modifications. Many (and for some, all) of these items have associated costs, some of which are subsidised by the Government. Individuals and families then begin a process of working out how they can afford to pay for the package and start a process of deciding which items they deem as *discretionary*. This study contributes to the existing literature by focusing on the strategies and trade-offs employed by people with chronic conditions to manage OOPC associated with health care and medicines. Unlike previous reviews, which primarily highlight the general challenges faced by individuals with chronic conditions, this study provides insight to specific strategies and financial decisions these people undertake.

This process is largely influenced by income, and for working Australians, their capacity to continue to earn an income. For people with chronic conditions and their carers, particularly those with multimorbidity, cancer, arthritis and asthma, this capacity may be greatly reduced by ill-health. However, the reduction in income is often not sufficient to qualify for concession cards enabling access to bulk-billing or the lower payments for PBS-subsidised medications. The impact of chronic conditions on the earning capacity of working Australians and their families in conjunction with the added burden of OOPC of healthcare and medicines is of great significance with the current cost of living crisis [59].

A number of policy mechanisms are intended to protect at-risk populations, including children, older adults, Aboriginal and Torres Strait Islander peoples, those living with disability, and living in rural and remote areas, and veterans [60]. The evidence from our review indicates that current mechanisms of subsidising consultations with providers and offering incentives for bulk-billing of at-risk populations are effectively reaching some of these groups, particularly those who can access bulk-billing GPs, specialist care through the public system, and Indigenous people who have access to care through ACCHOs and the Closing the Gap Policy. However, the evidence clearly also indicates that these policies are not reaching everyone who needs financial support to adhere to recommended healthcare regimens.

4.1. Consultations

Affordability of gap payments for GP consultations was raised studies up until 2019, although none since then; possibly reflective of changes to access during the COVID-19 pandemic, particularly reduced in-person access for CDM during this time, which was not cost-related [61]. At the same time access via telehealth was greatly enhanced from March 2020 and until October 2020 with all consultations bulk-billed [62]. Leaving the COVID-19 period aside, there has been a long-term trend reduction in the proportion of bulk-billed GP services [63]. In November 2023 the Government announced a trebling in the amount of the incentive payments for GPs to bulk-bill children under 16, pensioners and concession card holders, ranging from $20.65 in a metropolitan area to $39.65 in a very remote area. Preliminary data indicates that this has been effective in increasing access, particularly in regional and rural areas [64], although improvements are not as apparent in metropolitan areas. While these incentives may encourage more GPs to bulk-bill eligible patients, particularly in regional and rural areas, they do not reduce the gap fee paid by people ineligible for the bulk-billing incentive, or eligible people who are not bulk-billed. As there is significant geographic variation in the availability of bulk-billing practices [65], many patients may be unable to access bulk-billing near their home.

Cost was cited as a barrier to accessing specialist care. Frustration related to this was compounded by long waitlists for public specialist clinics. Specialist fees are driven by various patient-, specialist- and system-level factors and have great variability. To facilitate transparency in relation to these fees, and certainty for consumers, the Australian Government established the Medical Costs Finder website in 2019 to provide information about the range of fees for specialist consultations and treatments across Australia [66]. However, relatively few specialists have participated in the website, and it does not cover many procedures. While awareness of costs upfront may assist many people to prepare [67], our findings suggest that for many, it will make no difference as they cannot afford the gap payment in any event. As noted, Medicare includes two safety nets intended to limit calendar-year OOPCs for Medicare services provided outside hospital [68]. Our findings suggest that meeting the initial threshold is beyond the means of many people.

Specialists in private practice are free to determine their own fees according to their self-assessed expertise, seniority and reputation [69, 70]. The related issues of access and equity have been highlighted previously [69] and again in this review; however, access is not only limited by geography. An increased trend by specialists towards exclusive private practice outside the public hospital system [69] has contributed to lengthy public waitlists and increased affordability issues.

Cost was reported as a barrier to accessing allied health care for young people living with mental illness, people with cancer, diabetes and non-cancer pain. Through Medicare's Better Access Initiative, up to 10 individual and 10 group sessions with clinical psychologists are subsidised annually, and through the CDM program, benefits for up to five allied health consultations are paid in some circumstances; however, awareness of eligibility for subsidies was an issue for some, and the need for more than five subsidised appointments was raised by others. Many people could not afford to attend any appointment due either to the upfront fees, or the OOPC of the gap payment after the Medicare benefit was paid. Similar experiences were described for people seeking to access psychological support through the Better Access program [71]. Given that these programs cover a limited number of consultations a year, and that they often do not cover the full cost of, for example, an appointment with the physiotherapist or a psychologist, this can keep allied health services outside the reach of many people who would benefit from them.

Consistent with our findings, the recent report from a Senate review into dental services in Australia concluded that cost was the primary barrier to accessing dental care in the private sector, while long waitlists jeopardised timely access for public dental services [72]. While good dentition is important for everyone, it is more so for at-risk groups, including the geographically isolated, aged care residents, people with disabilities, and people with chronic conditions such as diabetes, CVD, HIV/AIDS, and those who take medications that impact dental health [73].

4.2. Medications

The literature indicates that people with chronic conditions prioritise taking prescribed medications yet may struggle to afford them. This review suggests that those reporting cost as a barrier to taking medications were largely those with multimorbidity, without full-time employment, retirees not eligible for concession cards, and people with conditions such as cancer and mental illness, where at times medications need to be trialled. These findings suggest that the safety-net mechanisms intended to limit cost barriers to PBS medications were not working effectively during the study period.

In 2023/24 the Government made several changes to the PBS intended to reduce costs to consumers, including reducing the general co-payment from $40 to $30 from 1 January 2024 (although it has since been CPI-indexed back to $31.60). It has also introduced 60-day prescribing for medications taken for select chronic health conditions. People who qualify for this policy in discussion with their prescriber, will pay the cost of the maximum general ($31.60) or concession ($7.70) for 60 days' medication instead of the previous 30 days. The saving is

Table 4
Results matrix by health condition.

				Consultations							Travel & associated costs					
	Study	Health condition/ population	Location	GP	Specialist	Allied Health N=8	Dental	Medications	Imaging/ Pathology	Equip/ Supplies	Travel	Parking	Fuel	Employment	Housing	PHI
Cancers	Essue 2015	End-of-life care	Urban	✓	✓			✓		✓	✓	✓		✓		✓
	McGrath 2015	Haematological malignancies	Rural		✓						✓					
	McGrath, 2016	Haematological malignancies	Rural					✓			✓					
	Kelada, 2020	Parents of childhood cancer survivors	Urban-rural					✓			✓	✓	✓	✓		
	Newton 2020	Cancer patients (breast, lung, prostate, colorectal)	Urban-rural					✓	✓		✓	✓		✓		✓
	Slavova-Azmanova 2020	Breast, prostate, colorectal or lung cancer	All		✓	✓		✓	✓		✓	✓	✓	✓		
	SkrabalRoss 2021	Adult cancer patients/ survivors	Rural – rem								✓			✓		
	Parker 2021	In remission from AML	Urban					✓			✓	✓		✓	✓	
	Gunn 2022	Carers of people with cancer	Reg/ Rural								✓	✓				
	Gulliver 2023	Cancer	All			✓					✓					
Arthritis	Hendry 2013	Rheumatoid arthritis	Urban	✓	✓	✓								✓		
	Berkovic 2021	Arthritis	Urban/ Rural		✓	✓		✓		✓	✓	✓	✓	✓	✓	✓
	Sutton, 2023	Osteoarthritis	Urban/ Rural			✓										
Chronic conditions in general and multimorbidity	Jeon, 2009	Carers & people with chronic conditions	Urban		✓			✓		✓	✓	✓		✓	✓	
	Jeon 2012	Older people with >3 chronic conditions	Urban-rural		✓			✓		✓	✓			✓	✓	✓
	Sav 2013	Carers & people with chronic conditions	Urban-rural					✓			✓			✓		
	Whitty, 2014	Carers and people with chronic conditions	Urban/ rural					✓						✓		
	Song, 2019	People with ≥1 chronic conditions and their carers	All	✓										✓		
	James 2011	Lymphoedema	Urban					✓								
	Cheung 2014	Insomnia	Urban		✓											
	Cuesta-Briand 2014	Type 2 diabetes mellitus (T2DM)	Urban		✓	✓					✓	✓	✓			
	Sanchez 2017	Cardiovascular disease	Urban				✓									
	Chou 2021	Obstructive sleep apnoea & CPAP	Urban							✓	✓	✓			✓	
	Frier 2022	T2DM	Rur -Remote					✓			✓					
	Hopkins 2022	Chronic non-cancer pain	Urb-rural			✓					✓			✓		
	Walkom, 2012	Women	All	✓			✓	✓			✓					
Population & disease specific	Frier 2021	Indigenous Australians with T2DM	Rural/ Remote					✓								

(*continued on next page*)

Table 4 (*continued*)

Study	Health condition/ population	Location	Consultations							Travel & associated costs					
			GP	Specialist	Allied Health N=8	Dental	Medications	Imaging/ Pathology	Equip/ Supplies	Travel	Parking	Fuel	Employment	Housing	PHI
Tynan, 2022	Indigenous people and oral health	Rural				✓			✓	✓					
Kunin, 2021	Older individuals (>65 years)	Urban		✓		✓									
McMillan, 2020	Young people living with mental illness	Urban					✓								
Savaglio, 2023	Young people living with mental illness & carers	Urban			✓					✓					
Medway, 2015	Carers of children with CKD	Urban-rural							✓	✓	✓	✓	✓	✓	
Scholes-Robertson 2023	Carers of people with CKD	Rural		✓			✓			✓			✓		
Farrar 2018	Parents of children with SMA	Urban							✓				✓	✓	
Henry 2023	People with cerebral palsy and carers	All							✓				✓	✓	
Koczwara, 2025	Adult cancer survivors with lymphoedema	All		✓					✓						
Omonaiye 2025	T2DM	All					✓								

less where the cost of the medication is below the maximum co-payment. In almost half the studies included in our review, participants reported cost as a barrier to accessing medications; many of these people would not currently qualify for this policy due to their particular health condition. Under current policy settings, a low-income couple who is ineligible for healthcare cards could pay $1647.90 (for 52 scripts) in co-payments before reaching the general safety net, and a further $227.20 (for 30 scripts) under the concessional safety net before receiving further medicines free of charge.

4.3. *Private health insurance*

The evidence in this review indicates that many who are paying for PHI, including pensioners, struggle to do so and in some cases resort to selling their homes. While PHI may enable faster access to elective hospital procedures, it exposes patients to OOPC for private in-hospital services. PHI does not assist with the costs of medical consultations outside hospital, there are limits on the number of services that will be covered, as well as total benefits payable. Some studies included in our review described people using PHI for allied health appointments and experiencing similar limitations to accessing appointments via CDM plans, such as unaffordable upfront costs and inadequate access to the amount of care required. Contributors to PHI schemes frequently receive much less than the cost of hospital and medical treatment and the cost of contributing has increased to an extent that is unaffordable for some and results in considerable hardship for others. The introduction of means testing of the government rebate for PHI in 2012 and indexation of the rebate to the consumer price index (separating it from the cost of premiums) in 2015 have each had a detrimental impact on the affordability of PHI for Australians [74].

4.4. *Regional variations*

Common challenges were identified across urban, regional and rural areas, although the nature of these differed, particularly in relation to the OOPC of travel and accommodation. Living close to health services enables access to the prevention, early diagnosis and treatment of chronic conditions [75]. While 30 % of the population lives in regional, rural and remote Australia [5], only 13 % of Australia's health workforce is located in these areas [76]. State- and territory-based PATS are designed to provide financial support for travel and accommodation to attend eligible specialist services that are not available within a specified distance from the residential address [77]. Our review highlighted the benefits of these schemes but also identified challenges related to navigating the system, waiting for reimbursement, and the inadequacy of subsides in covering OOPC for some people. A 2007 Senate inquiry into PATS [78] made a series of recommendations to improve the schemes, including simplifying administration and increasing subsidy rates; however, evidence still points to a lack of conformity in eligibility criteria for PATS and the level of financial support between jurisdictions [77]. Current accommodation rates across the States vary from $44 per night (SA) to $106.10 (WA), which is inadequate to obtain even basic accommodation in capital cities (except WA). This may contribute to further inequities in access to medical services for people living outside urban areas [77].

The burden of parking costs was raised as often for people living in urban areas as for those in rural areas, often in relation to parking to attend hospital outpatient clinics. While many hospitals have policies to subsidise parking for people with chronic conditions, their reach is clearly insufficient and needs to be improved.

4.5. *Limitations*

While three studies purposively recruited people from CALD backgrounds, OOPC experiences specifically related to this population were not reported. In 2021, 22.8 % of Australians use a language other than

Table 5
Matrix of findings in chronological order.

			Consultations							Travel etc					
Study	Population	Location	GP	Specialist	Allied Health	Dental	Medications	Imaging/ Pathology	Equipment Supplies	Travel (overall)	Parking	Fuel	Employment	Housing	PHI
Jeon, 2009	Carers & people with chronic conditions	Urban		✓			✓		✓	✓	✓		✓	✓	
James 2011	Lymphoedema	Urban					✓								
Jeon 2012	Older people with >3 chronic conditions	Urban-rural		✓			✓		✓	✓			✓	✓	✓
Hendry 2013	Rheumatoid arthritis	Urban	✓	✓	✓								✓		
Sav 2013	Carers & people with chronic conditions	Urban-rural					✓			✓			✓		
Walkom, 2012	Women	All	✓			✓	✓			✓					
Cheung 2014	Insomnia	Urban		✓											
Cuesta-Briand 2014	T2DM	Urban		✓	✓					✓	✓	✓			
Whitty, 2014	Carers and people with chronic conditions	Urban/rural					✓						✓		
Essue 2015	End-of-life care	Urban	✓	✓			✓		✓	✓	✓		✓		✓
McGrath 2015	Haematological malignancies	Rural		✓						✓					
Medway, 2015	Carers of children with CKD	Urban-rural							✓	✓	✓	✓	✓	✓	
McGrath, 2016	Haematological malignancies	Rural					✓			✓					
Sanchez 2017	Cardiovascular disease	Urban				✓									
Farrar 2018	Parents of children with spinal muscular atrophy (SMA)	Urban							✓				✓	✓	
Song, 2019	People with ≥1 chronic conditions and their carers	All	✓										✓		
Kelada, 2020	Parents of childhood cancer survivors	Urban-rural					✓			✓	✓	✓	✓		
McMillan, 2020	Young people living with mental illness	Urban					✓								
Newton 2020	Cancer patients (breast, lung, prostate, colorectal)	Urban-rural					✓	✓		✓	✓		✓		✓
Slavova-Azmanova 2020	Breast, prostate, colorectal or lung cancer	All		✓	✓		✓	✓		✓	✓	✓	✓		
Berkovic 2021	Arthritis	Urban/Rural		✓	✓		✓		✓	✓	✓	✓	✓	✓	✓
Chou 2021	Obstructive sleep apnoea & CPAP	Urban							✓	✓	✓	✓		✓	
Frier 2021	Indigenous Australians with T2DM	Rural/Remote					✓								
Kunin, 2021	Older individuals (>65 years)	Urban		✓		✓									
Parker 2021	In remission from acute myeloid leukemia (AML)	Urban					✓			✓	✓		✓	✓	
SkrabalRoss 2021	Adult cancer patients/survivors	Rural – rem								✓			✓		
Frier 2022	T2DM	Rur -Remote					✓			✓					
Gunn 2022	Carers of people with cancer	Reg/Rural								✓					
Hopkins 2022	Chronic non-cancer pain	Urb-rural			✓					✓			✓		
Sinclair 2022	Primary dysmenorrhea	Urban-rural					✓								
Tynan, 2022	Oral health	Rural				✓			✓	✓					
Gulliver 2023	Cancer	All			✓					✓					
Savaglio, 2023	Young people living with mental illness & carers	Urban			✓					✓					
Scholes-Robertson 2023	Carers of people with CKD	Rural		✓			✓			✓			✓		
Sutton, 2023	Osteoarthritis	Urban/Rural			✓										
Henry 2023	People with cerebral palsy and carers	All areas							✓				✓	✓	
Koczwara, 2025	Adult cancer survivors with lymphoedema	All areas		✓					✓						
Omonaiye 2025	T2DM	All areas					✓								

Table 6
Population groups included in studies.

Study population	Study reference	Number of studies (n)
People living with various chronic conditions and comorbidities, and their carers	[15,22,26,32,48–50]	7
People living with socioeconomic disadvantage	[16,35,36,48]	4
Aboriginal and Torres Strait Islander peoples	[15,35,42]	3
Culturally and Linguistically Diverse (CALD) groups	[15,22]	3
Young people (14-25 years, 10-25 years)	[39,40]	2
Parents caring for children	[27,38,45]	3
Women	[41]	1
Older people (≥ 50 years, ≥ 65 years)	[48,50]	2
People living in regional, rural and remote areas	[25,28,29,36,42,52]	6

Box 1
PBS Safety Net Thresholds, 1 January 2025*.

Threshold
$277.20 for concession card holders – after which medicines will be free of charge.
$1,694.00 for general patients – after which medicines will cost $7.70 per prescription.
Families can meet the threshold sooner if they combine their individual PBS amounts. **
Before meeting the threshold, each medicine will cost up to:
$7.70 for concession card holders
$31.60 for general patients

[*] Thresholds are adjusted annually in line with the Consumer Price Index.

[**] Note, in order to ensure the benefits of reaching the safety net are received, consumers must provide evidence from a pharmacy (or in some cases several pharmacies) and apply for a PBS Safety Net card.

English at home; of these, 15 % spoke little or no English, representing 3.4 % of the population [79]. It is critical to understand the impact of OOPC on these Australians who experience high prevalence of chronic disease, many of whom struggle to navigate the system due to cultural and language barriers [80].

5. Conclusion

The problem of OOPC of health care in Australia has received considerable attention, through both the examination of large-scale data and qualitative studies focusing on single diseases or specific population groups. This study links the two levels of analysis, providing a broad lens through which to view the impact of Australian health policies aimed at optimising access to healthcare and medicines through reducing OOPCs. Our findings indicate that these policies result in highly variable experiences among Australians living with chronic conditions. While they reduce financial burden related to health care for many people, there are distinct challenges for groups who do not qualify for the concessional threshold, including self-funded retirees and people working part-time due to illness, who may suffer disproportionate consequences of OOPCs. The fact that some Australians with chronic conditions are having to make choices between basic necessities, such as food, and health care is more than surprising considering Australia's ranking amongst the best healthcare systems in the world. It is critical to explore the experiences of people with chronic conditions further. While the frequency with which issues are raised is a good indicator of their relevance and the data provide insight into the choices that people face, insight into how people prioritise and decide what to trade-off and how these decisions are impacted by income level (or changing levels) and disease severity is critical to ensure that Australian health policy lives up to its reputation and is responsive to the needs of those living with chronic conditions.

CRediT authorship contribution statement

Jane Desborough: Writing – review & editing, Writing – original draft, Validation, Supervision, Project administration, Methodology, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Charles Maskell-Knight:** Writing – review & editing, Formal analysis. **Shelley Wang:** Writing – review & editing, Methodology, Data curation, Conceptualization. **Anne Parkinson:** Writing – review & editing, Validation, Formal analysis, Data curation, Conceptualization. **Danielle Butler:** Writing – review & editing, Methodology, Formal analysis. **Hsei-Di Law:** Writing – review & editing, Methodology, Formal analysis. **Kamania Butler:** Writing – review & editing, Methodology, Formal analysis. **Leanne Watts:** Writing – review & editing, Methodology, Formal analysis. **Elisabeth Huynh:** Writing – review & editing, Methodology, Formal analysis. **Fiona Hodson:** Writing – review & editing, Methodology, Formal analysis. **Samar Ibrahim:** Writing – review & editing, Methodology, Formal analysis. **Julie Veitch:** Writing – review & editing, Methodology, Formal analysis. **Jillian Kingsford-Smith:** Writing – review & editing, Formal analysis. **Michael Kidd:** Writing – review & editing. **Cam Donaldson:** Writing – review & editing, Methodology, Formal analysis.

Declaration of competing interest

The authors declare that they have no competing interests

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Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.healthpol.2025.105359.

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