Life Course Centre

WORKING PAPER SERIES

No. 2026-21

July 2026

Priorities of People Living with Narcolepsy in Australia

Awareness, Care Access, and Lived Experience

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Australian Research Council

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Research Summary

Why was the research done?

Narcolepsy is a lifelong neurological condition that affects the sleep and wake cycle. It is often misunderstood, both by the public and by health professionals, and many people wait years to be correctly diagnosed. Most research on narcolepsy in Australia has focused on testing medications, which means the views and priorities of people who live with the condition have rarely been captured. We wanted to hear directly from people living with narcolepsy in Australia about the challenges they face day to day, and about their experiences of being diagnosed and cared for, in their own words.

What were the key findings?

We looked at survey responses from 165 adults living with narcolepsy across Australia. Their challenges fell into four main areas: **the daily impact of the condition** on work, driving, parenting, finances, and mental health; **a widespread lack of awareness and understanding among the public and health professionals**, which often led to people being unfairly judged as lazy; **limited social support**, including difficulty getting recognised for disability assistance and few chances to connect with others who understand the condition; and **problems accessing care and treatment**, such as shortages of specialists (especially in rural areas), long delays, misdiagnosis, and medications that were unavailable or unaffordable. Experiences with health professionals were a particular concern. While most people had received some advice about managing their narcolepsy, only 12% were satisfied with it. Care tended to focus almost entirely on medication, with little attention given to lifestyle, driving, relationships, or mental health.

What does this mean for policy and practice?

The findings point to clear opportunities to improve care and support. These include better education and awareness for doctors and other health professionals so that narcolepsy is recognised earlier and referrals are clearer; expanding access to effective, affordable medications and easing restrictive pharmacy rules; and recognising narcolepsy more consistently within disability and social support systems. Public awareness efforts are also needed to reduce stigma and misunderstanding in the wider community. Just as importantly, care should extend beyond medication to include psychological support, peer connection, practical guidance on driving and work, and support for parents. Involving people living with narcolepsy in designing these improvements will help ensure that services genuinely meet their needs.

Citation

Schokman, A., Christie, K., Chadwick, M., Lindsay, H., Stratton, E., Edmed, S., & Glozier, N. (2026). 'Priorities of People Living with Narcolepsy in Australia: Awareness, Care Access, and Lived Experience', Life Course Centre Working Paper Series, 2026-21. Institute for Social Science Research, The University of Queensland.

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Acknowledgements/Funding Sources

We acknowledge the contributions of author Michelle Chadwick, who designed and distributed the survey to collect information on frequently asked questions, complaints, and challenges reported by caregivers and persons with narcolepsy. We also acknowledge the contributions of Hypersomnolence Australia for recruitment and distribution of the survey.

This research was supported by the Australian Government through the Australian Research Council's Centre of Excellence for Children and Families over the Life Course (Project ID CE200100025).

We acknowledge the Traditional Custodians of the lands on which we work and live across Australia. We pay our respects to Elders past and present and recognise their continued connections to land, sea and community.

Priorities of People Living with Narcolepsy in Australia: Awareness, Care Access, and Lived Experience

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Introduction

Narcolepsy is a lifelong neurological disorder of the sleep–wake cycle that affects approximately 1–5 per 10,000 individuals worldwide (1). Traditionally described through the symptom pentad-excessive daytime sleepiness (EDS), cataplexy, sleep paralysis, hypnagogic and hypnopompic hallucinations, and disrupted nocturnal sleep, the condition is increasingly understood to involve broader functional, psychosocial, and emotional impacts (2, 3).

People with narcolepsy (PwN) often experience substantial impairments in daily activities such as studying, working, driving, and maintaining social participation, which collectively reduce quality of life (4-6). Beyond clinical symptoms, narcolepsy is frequently associated with stigma, strained relationships, and mental health difficulties such as depression and anxiety, reflecting the substantial psychosocial burden of the condition (6-8).

Despite its profound impact, narcolepsy remains poorly recognised and widely misunderstood. Public awareness is limited, and media portrayals often reinforce misconceptions, contributing to social invisibility and stigma (9). Knowledge gaps among healthcare professionals are also well documented. Even among sleep specialists, uncertainty in identifying key symptoms persists (10). Mismatches between clinical terminology and patient language, such as collapsing distinct experiences of fatigue, sleep attacks, and drowsiness under "EDS", can impede communication and delay diagnosis (11). Narcolepsy typically begins in childhood, yet diagnostic delays of 5–15 years remain common (12), contributing to emotional distress and prolonged periods of unmet need.

Research on narcolepsy in Australia has primarily focused on clinical trials for novel interventions. Accordingly, patient perspectives and priorities are largely missing from the research. As healthcare shifts toward person-centred models, integrating lived experience into research and service design is essential. Existing quantitative measures assume a set of concerns and domains, and because these were not informed by lived experience from the outset, do not always capture the range of priorities and issues that are most front of mind for those living with Narcolepsy. In addition to the need to develop better patient-reported outcome measures that have been co-designed with people with lived experience of narcolepsy (13), there is also a strong need for qualitative work to understand the spectrum of experiences, not otherwise constrained by clinician-framed elicitation of clinical symptoms.
Advocacy organisations play a central role in bridging clinical care with lived experience, raising awareness, informing research priorities, and promoting policy change(14).

Using qualitative data from a survey collected from Hypersomnolence Australia, a not-for-profit organisation, this study aimed to:

1. Identify the main challenges persons with narcolepsy face day-to-day when seeking care for narcolepsy, in their own words; and
2. Explore how persons with narcolepsy perceived healthcare professionals' knowledge of narcolepsy, and how that shapes diagnostic and care experiences in Australia.

3. Explore multilevel factors (spanning individual, interpersonal, organisational, community and societal levels) affecting diagnostic and care experiences, and the lived impacts of narcolepsy.

By highlighting patient-reported barriers, this research seeks to inform improvements in clinical practice, public awareness, and policy development, ultimately supporting more equitable and person-centred narcolepsy care.

Methods

Study design and ethics

Mixed-methods retrospective analysis of open-response questions embedded within a cross-sectional survey. This survey was accessible via Hypersomnolence Australia's website (https://www.hypersomnolenceaustralia.org.au). Ethical approval was obtained from the Human Research Ethics Committee (HREC) at The University of Sydney (reference: 2022/HE000126).

Survey questions

Three open-response questions, from a broader 47-item online survey, were used to assess issues based on the lived experiences of individuals with narcolepsy. These three open-response questions were: 1) "What are your biggest concerns/hurdles?", which were used to assess issues based on the issues you think need addressing regarding Narcolepsy? 2) "What advice did your doctor give you about managing Narcolepsy? And 3) What advice do you think is important for people to be given when they are diagnosed with Narcolepsy (and perhaps other sleep disorders) that you did NOT receive when you were diagnosed?"). There were no character/word limit restrictions for responses. Seven binary questions exploring the advice received from a specialist and the level of satisfaction with this advice were also analysed.

Recruitment & Participants

Study inclusion criteria were: self-reported diagnosis of narcolepsy, adult (over 16) and living in Australia, exclusion criteria were: diagnosis of Idiopathic Hypersomnia. The online survey was completed independently without researcher contact and was open from November 2021 to June 2023. Participation was anonymous and limited to one response per person. In total, 165 PwN (79% female; 38% Narcolepsy Type 1) completed the survey. Response rate could not be calculated because the number of individuals who viewed the survey but did not complete it was unknown.

Data analysis

Only persons with a self-reported diagnosis of narcolepsy (type 1 and 2) were included in our analysis. Three content analyses were conducted on the open-response questions. Content analysis followed a four-step process as per Bangsten (2016) (15): 1) decontextualisation (identifying meaningful units and coding responses); 2) recontextualization (removing data misaligned with study aims); 3) categorisation (assigning categories to aligned responses), and; 4) compilation (integrating data into a coherent narrative). Categories were cross-coded by four authors from diverse backgrounds: the head of Hypersomnolence Australia (MC), a lived-experience researcher (AS), and two research assistants (HL & KC). Discrepancies were resolved through discussion

until consensus was reached. Codebooks were merged after agreement. Reporting adhered to the Standard for Reporting Qualitative Research (SRQR) (See SUPPLEMENTARY C) (16). Additionally, categories were then mapped and interpreted across different levels of a public health-oriented socioecological model. Priorities were inferred from salience and recurrence of coded units.

Results

Participant characteristics

The survey was completed by 165 PwN from Australia. Of these, n = 63 (38.2%) had cataplexy (NT1), and n = 131 (79.4%) were female. Most participants, n = 150 (90.9%), reported diagnoses from sleep specialists, with n = 97 (58.8%) reporting symptoms starting in their childhood. Other quantitative analysis from the same survey has been published elsewhere (17).

Table 1: Demographic of participants

	Participants	
	NT1	NT2
n, (%)	63 (38.2%)	102 (61.8%)
Female (n, %)	52 (82.5%)	79 (77.5%)
Age (n, %)		
<21	5 (7.9%)	7 (6.9%)
21 – 30	19 (30.2%)	34 (33.3%)
31 – 40	24 (38.1%)	34 (33.3%)
41 – 50	10 (15.9%)	17 (16.7%)
51- 60	5 (7.9%)	10 (9.8%)
>60	0 (0%)	0 (0%)
Symptom onset < 18 years (n,%)	37 (58.7%)	60 (58.8%)

Objective 1: Exploring the main challenges of living with narcolepsy

Research Question 1: Summary of content analysis.

One hundred and thirty-three participants (81%) responded to the question about what their main challenge of living with narcolepsy. Some participants reported more than one concern, yielding 223 different qualitative data points. Content analysis yielded four primary categories: limited access to care (n = 33, 14.8%); awareness and education among the public and healthcare professionals (n = 70, 31.4%), lack of social support (n = 44; 19.7%), and daily impact of narcolepsy (n = 76, 34%). A description of these categories and subcategories, as well as example quotes, is presented in Table 1.

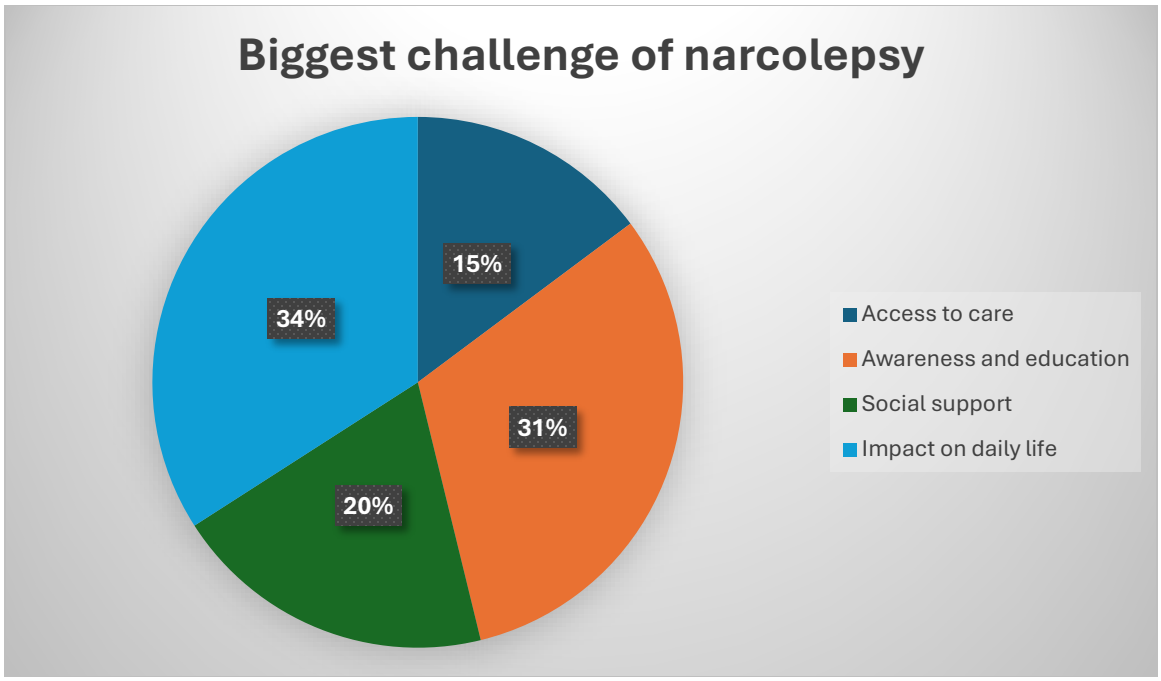

Table 1. Summary and Exemplar Quotes from Content 1 – **Primary Challenges Faced by Individuals with Narcolepsy [Q 47]**

Category	Sub-Category	Summary	Exemplar quotation
Access to care	Limited medication options	Available medications for narcolepsy are considered ineffective. Newer medication options are not accessible.	"That many of the medications recommended by treatment guidelines are not TGA approved, or not on the PBS, making them inaccessible." **[ID67FNT2]**
	Collecting medications	Pharmacy regulation complicates collecting medication.	"You can't take the script to different pharmacies. This affects travel and moving. I feel like a criminal who can't leave town and has to check in once a month. I have hoarded my medication to make sure I always have enough." **[ID67FNT2]**
	Cost of medications	The cost of medications like sodium oxybate is prohibitive despite potential benefits.	"My doctor wants me to try Xyrem or Zenivol to get better quality sleep, but both medications are too expensive..." **[ID152FNT2]**
	Specialist shortages	Long wait times to access public care(i.e sleep studies) and	"Faster access to public sleep specialists. Currently on the waitlist for one at

		specialists with expertise in narcolepsy.	[name of clinic]. Been waiting over 3 years." **[ID75FNT2]**
Awareness and education	Lack of awareness among public	Narcolepsy often disregarded as laziness or actively falling asleep, with little awareness of often severe impact on mental and physical health.	"People need to understand narcolepsy isn't always sleeping or being "lazy". We can't control it. It can have SEVERE effects on a person's mental and physical health, especially young people." **[ID133FNT1]**
	Public stigma and discrimination	Common misconceptions lead to stigmatisation. Judgment from employers, and even family members contribute to feelings of isolation and frustration.	"Living in a state of fatigue is a struggle on its own. Being negatively judged and criticised for it makes it that much harder to deal with on an emotional level. My favourite comments over the years have been, "lazy, useless, pathetic, weak..." and the number one spot goes to, "you should be ashamed of yourself" (for feeling tired in my 20s)" **[ID140FNT2]**
	Healthcare professionals' knowledge of narcolepsy	Delayed diagnoses, incorrect treatments, and lack of support attributed to healthcare professionals lack of knowledge/awareness of narcolepsy. PwN appear to have struggle to find doctors who take their condition seriously.	"Due to doctors dismissing me and misdiagnosing me with Chronic Fatigue instead of doing a sleep study, it took me 12 years and hundreds of hours of my own research and self-education to demand a referral to a sleep specialist." **[ID86FNT2]**
Navigating Social	Government disability support	Australian social support system (i.e Centrelink or NDIS) failed to recognise the narcolepsy or it's impact, prohibiting access to financial and social support.	I hope if I fall asleep at the wheel, I don't crash into anyone. Except for maybe whoever decided Narcolepsy isn't a disability. I've had it with this s**t, there's nothing left for me to try now, and my future isn't

			exactly bright either. **[ID72FNT1]**
	Relationship challenges	Difficulties maintaining friendships and relationships. Symptoms include brain fog and irritability, strained relationships, leading to social withdrawal.	"The unfair added strain placed on my wife from my sleeping all the time." **[ID70MNT2]**
Personal impact	Daily limitations	Narcolepsy disrupts daily tasks such as driving, work, and family care, with unpredictable fatigue often limiting social plans and overall productivity.	"It's sometimes hard to also make nighttime plans because each day is slightly different and can impact your driving ability." **[ID49FNT2]**
	Parenting challenges / Family dynamic	Barriers in family dynamics. New mothers facing difficulties with lack of information and support balancing sleep, caregiving, and medication.	"The fact that symptoms can get worse for pregnant women and mums after giving birth." **[ID33FNT1]**
	Working pressure	Overwork expectations stress those seeking work-life balance due to reduced functional capacity.	"Working in busy and intense area and getting overwhelming fatigue so have no energy for any other life activities or exercise, resulting in exacerbation of depression." **[ID102FNT2]**
	Financial stability	Uncertainty about full-time work threatens financial security.	"I don't feel I can safely work full-time. The future does not look bright for people with narcolepsy, every day will be a struggle and not just from the constant crushing symptoms." **[ID148FNT2]**
	Mental health problems	Depression, anxiety, and isolation, feeling misunderstood and unsupported, which	"I had lost all hope and tried to take my own life several times. Being diagnosed earlier would have made a

	severely affected self-esteem and overall outlook on life.	huge difference to my life" **[ID90FNT1]**

1. **Narrative synthesis of primary challenges faced by individuals with Narcolepsy**

1.1 Access to Care

Of the PwN who identified primary challenges related to access to care (N = 33), the majority of participants (n=17) highlighted barriers to accessing treatment, particularly the limited availability of medications approved by regulatory bodies in Australia or subsidised via the public healthcare system (i.e Pharmaceutical Benefits Scheme PBS). One participant noted that many guideline-recommended medications are inaccessible and not registered with regulatory bodies in Australia (i.e TGA and PBS): *"...many of the medications recommended by treatment guidelines are not TGA approved, or not on the PBS..."* [#67, Female, NT2].

Participants (n=7) described challenges with collecting medication, including the waiting time it takes to be approved for better medication: *"the current dose of Dexamphetamine that I am taking is starting to wear off, causing an awkward and uncomfortable transition period until I can be approved for Modafinil…."* [#32, Female, NT1]. Strict pharmacy dispensing rules further complicate access to collect medication, with one individual questioning the necessity of restricted pharmacy selection and collection windows: *"Why do I have to only go to one pharmacy? They don't check my ID and have said I can have someone else collect it when I can't… I have run out in the past because of missing the narrow collection window."* [#67, Female, NT2]. Living rurally also posed obstacles, with one respondent stating: *"Personally not having any specialists in Tasmania at all that deal with narcolepsy."* [#65, Female, NT2]. Shortage in the number of specialists handling narcolepsy in certain areas (n=9) was perceived to cause delayed diagnosis and treatment.

1.2 Awareness and Education of Narcolepsy

Participants (n=24) reported limited public understanding of narcolepsy, often misinterpreted as laziness or simple drowsiness, downplaying its broader impact. One participant explained their narcolepsy was not adequately explained by terms like excessive daytime sleepiness, and instead the challenges were better described using terms like "irritability, moodiness, memory impacts" [ID82FNT2]. Another added, "*Getting people to understand - the full impact, not just 'you can fall asleep whenever you want*'" [ID80FNT1].

Participants (n=19) described experiencing stigma and discrimination related to narcolepsy. Experiences of judgment from employers, peers, and family members were common. One participant shared, "*My favourite comments over the years have been, 'lazy, useless, pathetic, weak...' and 'you should be ashamed of yourself' (for feeling tired in my 20s)*" [ID140FNT2]. Another reported difficulty is being believed by healthcare providers: "*People, including doctors,*

say you're just not getting enough sleep. But I can lay in bed for 12 hours and nap in the afternoon and I'm still exhausted. We say I have episodes, people assume I'm just lazy…" [ID138FNT1].

Doctor's knowledge gaps and unclear help-seeking pathways were also highlighted (n=27), contributing to delays in diagnosis, incorrect treatments, and inadequate support. One participant noted, "*I went 15 years before being sent to a sleep specialist*" [ID151_M_NT2]. Limited provider knowledge about support services was also mentioned: "*Doctors unable to adequately provide information/connection to support groups, etc.*" [ID2_F_NT1].
Participants emphasised the need for broader education efforts targeting the public and healthcare providers. They highlighted improved awareness in diverse settings and recognising narcolepsy as a disability as key steps to reducing stigma and improving care outcomes.

1.3 Social Support
Participants (n=26) described limited access to government disability support, noting that narcolepsy is not widely recognised by services such as Centrelink or NDIS. The lack of recognition was perceived as a barrier to obtaining financial and caregiving support. One participant remarked, "*I have not applied because I have heard it is not likely that I will be successful*" [ID72FNT1].

Relationship challenges were also highlighted (n=18). Participants described difficulties maintaining friendships and personal relationships, often due to cognitive impacts such as brain fog and irritability, which contribute to social withdrawal. One participant noted, "*The unfair added strain placed on my wife from me sleeping all the time*" [ID70MNT2]. Another mentioned, "*Associated cognitive impact from interrupted sleep, autonomic behaviours, associated comorbidities of interrupted sleep, i.e., falls, mistakes, micro sleeps, impact on social life*" [ID149FNT2].

1.4 Personal Impact
Participants (n=33) described narcolepsy as significantly limiting their ability to manage daily tasks, work, and family responsibilities. Impaired driving ability was frequently reported to fluctuate, restrict social activities, and create additional stress in maintaining routines.
Parenting challenges were also highlighted (n=6), particularly for new mothers who reported limited information and support in managing their condition. One participant explained, "*Symptoms can worsen for pregnant women and new mothers*" [ID33FNT1]. Another shared, "*How exhausting it is being a parent with narcolepsy, how to manage my energy so I can play with my kids more often*" [ID11FNT2].

Workplace pressures added to these challenges (n=9), with participants describing work-related fatigue reducing their capacity to engage in other life activities. One participant shared, "*Working in a busy area leaves me too fatigued for other activities, worsening my depression*" [ID102FNT2]. Financial instability was another concern (n=12), with participants expressing uncertainty about sustaining full-time employment. One individual reflected, "*I don't feel I can safely work full-time. The future feels like a constant struggle*" [ID148FNT2].

Participants (n=16) described severe mental health impacts from narcolepsy, including depression, anxiety, and isolation. Many felt misunderstood and unsupported, as one noted, *"Family & friends*

don't understand & therefore are not as supportive as I really need them to be" [ID18FNT2], and another shared, *"the loneliness, depression, anxiety that comes with all of the symptoms"* [ID56FNT2]. Some expressed hopelessness after years of misdiagnosis, with one stating, *"I had lost all hope and tried to take my own life several times"* [ID90FNT1].

Objective 2: Exploring how perceived healthcare professionals' knowledge shapes diagnostic and care experiences in Australia

Quantitative

Table 2: Proportion of participants answering yes to survey questions around advice from their treating specialist

	Participants		
	NT1 (n=63)	NT2 (n=102)	Total (n=165)
Did your doctor give you advice about managing your narcolepsy? n,%	57 (90.5%)	89 (87.3%)	146 (88.5%)
Have you received advice from your doctor about:			
Medications and interaction	16 (28.1%)	30 (33.7%)	46 (31.5%)
Nighttime sleep (sleep hygiene and management)	54 (93.1%)	81 (91.0%)	135 (91.8%)
Caffeine and Substance Use	20 (35.1%)	38 (42.7%)	58 (39.7%)
Driving and legal implications	42 (73.6%)	60 (67.4%)	102 (69.9%)
Lifestyle and general health	33 (57.9%)	44 (49.4%)	77 (52.7%)
Are you satisfied with the advice your doctor gave you to manage your narcolepsy?	9 (14.3%)	11 (10.8%)	20 (12.1%)

Despite a high number (n = 146, 89%) of participants self-reporting that they received advice from their doctor about managing narcolepsy, only 12% were satisfied with the advice received. Concerningly, almost a third of individuals reported not having received advice about driving and the legal implications that follow from driving with a diagnosis of narcolepsy.

Summary of content analysis.

The content analysis yielded four categories of advice received from specialists regarding narcolepsy management, which included medication, lifestyle, sleep hygiene, and other advice. For advice omitted regarding narcolepsy management, six categories were identified: gaps in advice for medication, establishing a multidisciplinary care team, relationship impact, peer support groups, comorbidities, and other omitted advice. A description of these categories and subcategories, as well as example quotes, is presented in Table 2.

Table 2. Summary and Exemplar Quotes about PwN's Perceptions' of Health workers' Knowledge of Narcolepsy: Advice PwN received from their specialist, AND, advice PwN felt was missing and wanted to hear more about from their specialist.

Category	Sub-Category	Summary	Exemplar quotation
Advice PwN received from their specialist (Given advice)	Medication	Doctors often emphasised the reliance on medication for managing narcolepsy, sometimes warning about potential dependency or side effects.	"The medication is addictive & not a long-term solution" **[ID156FNT2]** "You have narcolepsy, you need to take drugs to keep you awake and try not to eat because you'll end up obese." **[ID138FNT1]**
	Lifestyle	Participants reported that doctors offered lifestyle advice, such as increasing sunlight exposure or using blue light glasses. However, other advice appeared simplistic or linked narcolepsy directly to weight concerns, which felt unhelpful or stigmatizing.	"Says get sunlight in eyeballs especially in the morning or buy blue light glasses" **[ID108FNT2]** "I have N1 and am therefore overweight" **[ID52FNT1]**
	Sleep hygiene	Participants described receiving only general sleep hygiene advice, with limited practical or personalized guidance.	"I was only given very generic advice - eg. try naps, make sure sleep hygiene is good, but nothing specific" **[ID67FNT2]**
	Others	Participants reported receiving unusual advice they found unhelpful (i.e references to historical images), or had better outcomes with previous physicians who offered more effective management strategies.	"He showed me pictures of old paintings of a woman having a narco dream/hallucination" **[ID141FNT2]** "This advice was from first sleep specialist without a lab before narcolepsy diagnosis. When my doctor hadn't retired, I was managing my disorder and life a lot better." **[ID65FNT2]**
Advice PwN felt was missing and wanted to hear more about	Medication	Participants highlighted the absence of information regarding the long-term effects of prescribed medications.	"What the long term effects may be of taking certain medications" **[ID148FNT2]**

from their specialist	Establishing a multidisciplinary care team	Participants expressed a need for referrals to specialists who could help manage practical aspects of living with narcolepsy.	"Which other specialists might be able to help me manage the practical implications of having narcolepsy" **[ID92MNT1]**
	Relationship impact	Participants noted a lack of guidance on how narcolepsy could affect relationships with family and friends.	"The psychological effects and the impact on family/friends" **[ID15FNT1]**
	Peer support group	Participants emphasised the importance of connecting with others who share the diagnosis for emotional and practical support.	"The importance of finding others who have this Diagnosis, joining groups on facebook as you need someone to talk to who is or has gone through what you are." **[ID48MNT1]**
	Comorbidities	Participants mentioned a lack of information on mental health impacts and coping with the psychological burden of living with a chronic condition.	"The affects on your mental health, the diagnosis and living with a chronic condition is a lot to deal with" **[ID124FNT1]**
	Others	Additional unmet needs included practical strategies like the Spoon Theory, understanding circadian rhythms, and recognizing the broader health effects of disrupted slow-wave sleep.	"A run down on the Spoon Theory, and some tactics for managing expectations from yourself and others. General stuff about how it's not just being lazy." **[ID97FNT1]** "How natural light affects your circadian rhythm and how narcolepsy means you don't get a lot of slow wave sleep which has a lot of health effects" **[ID44FNT1]**

2. Narrative synthesis exploring how PwN perceive Sleep Specialists' Knowledge Narcolepsy

2.1 Advice PwN received from their specialist

Participants reported mixed experiences with specialist advice. A participant received practical suggestions such as increasing sunlight exposure or using blue light glasses, while others found the guidance overly simplistic or unhelpful, for example, *"I was only given very generic advice, like try naps, make sure sleep hygiene is good"* [ID67_F_NT2]. Medication was often emphasized, sometimes with discouraging or stigmatizing warnings, such as *"You have narcolepsy, you need to take drugs to keep you awake and try not to eat because you'll end up obese"* [ID138_F_NT1].

Advice PwN felt was missing and wanted to hear more about from their specialist
Participants expressed a desire for more comprehensive and individualized support. They wanted clearer information about long-term medication effects [ID148FNT2], referrals to other professionals to address practical and psychosocial needs [ID92MNT1], and acknowledgment of relationship and mental health challenges [ID15FNT1; ID124FNT1]. Several emphasized the value of connecting with others who have it, noting the importance of peer support [ID48MNT1]. Others sought greater understanding of circadian rhythms, the Spoon Theory, and the health effects of disrupted slow-wave sleep [ID44FNT1; ID97FNT1]. Overall, participants felt that advice often lacked depth and personal relevance, leaving many unmet informational and emotional needs.

Objective 3: Interpret findings within a socioecological framework, to identify individual, interpersonal, organisational, community and societal factors affecting narcolepsy care outcomes and personal impacts of living with narcolepsy

Figure 1 presents a socioecological conceptualisation of factors influencing the experiences of people with narcolepsy in Australia, derived from the above qualitative analysis. The framework illustrates barriers to accessing care, the role of specialist knowledge in shaping diagnostic and treatment pathways, and the broader challenges of living with narcolepsy. Factors are organised across five levels: individual, interpersonal, organisational/practitioner, community, and societal/policy.

While individual-level factors such as financial constraints and comorbidities were noted, participants predominantly emphasised external influences, including stigma, limited clinician expertise, fragmented referral pathways, and systemic issues such as medication affordability, specialist shortages, and inadequate recognition within disability and social support systems. At the societal level, cultural values prioritising productivity and low public awareness emerged as key challenges.

Discussion

This study explored the lived experiences of people with narcolepsy in Australia, focusing on their everyday challenges and diagnostic and care experiences. This study uniquely captures the perspectives of people with narcolepsy in their own words. Participants described substantial

barriers to accessing appropriate care and treatment, as well as the broader multi-domain impacts of living with narcolepsy. Results also revealed perceptions of limited community awareness and varied health professionals' knowledge of the condition. Findings also contribute to evidence showing that narcolepsy exerts a substantial but frequently under-recognised impact on quality of life (4, 18, 19), and that people with narcolepsy face substantial multilevel barriers to social and economic inclusion, along with challenges accessing high-quality patient-centred care across the journey from symptom onset through to ongoing management of Narcolepsy. These findings highlight clear priorities for improved recognition of impact of narcolepsy across multiple domains, increased community and professional awareness, and more accessible, coordinated models of care across the diagnostic and management pathway.

Priorities emerging from the challenges faced by individuals with Narcolepsy

This study demonstrated the complex challenges associated with living with narcolepsy and its far-reaching personal impacts. Key challenges centred on difficulties accessing appropriate care and treatment, navigating social interactions and health systems in contexts where community members and health professionals often lacked awareness or understanding of narcolepsy, and obtaining adequate financial and relational support. Participants also articulated the profound personal and day-to-day impacts of living with narcolepsy. Together, these findings demonstrate how the challenges of living with narcolepsy extends well beyond its clinical symptoms, highlighting priorities for improved access to effective treatment and care, greater awareness across community and organisational systems (e.g., health services, employers, social services and support), and more comprehensive support across the multiple domains impacted by living with narcolepsy.

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Priorities emerging from experiences with health care providers

Participants reported mixed, but largely inadequate encounters with sleep specialists in the management of narcolepsy. These accounts highlight opportunities to improve clinical advice by incorporating the perspectives and priorities of people living with narcolepsy themselves. Importantly, participants emphasised the need for guidance that addresses not only clinical symptom management, but also the broader physical (e.g., long term effects of medication use, comorbidities), social (e.g., relational support, peer connection), and psychological challenges associated with Narcolepsy, highlighting priorities for person-centred models of care that extend beyond symptom management.

A socioecological interpretation of findings

Public-health-oriented socioecological models, which depict individual, interpersonal, organisational, community, and policy levels, provide a useful lens for understanding how diagnostic and care experiences of narcolepsy, and personal impacts, are shaped by multilevel, interacting determinants. The conceptualisation developed for this study demonstrates how individual, social, organisational, community and societal determinants influence diagnostic delays, care experiences, and life-course disruptions for people with narcolepsy. Viewing these findings within a socioecological framework clarifies levers for change and intervention targets across multiple levels. This framing also reinforces that narcolepsy-related challenges are not

"personal failings", rather, that interactions across interpersonal relationships, health system structures, and broader societal and policy contexts influence the barriers and challenges described by people with narcolepsy. Notably, in this study, participants identified predominantly external determinants.

Society and policy

Many challenges and care pathway barriers were situated at the societal and policy level, including restricted access to evidence-based medications and specialist services. In Australia, access to evidence-based medication is inconsistent: Dexamphetamine remains the only first-line subsidised treatment for excessive daytime sleepiness (EDS), while modafinil and armodafinil (internationally preferred alternatives) are secondary options, despite repeated advocacy for their first-line use. Additionally, stringent criteria, shortages, and the lack of PBS listing for sodium oxybate create ongoing access barriers that disproportionately affect rural and lower-income individuals (20). Restrictive pharmacy regulations and prescribing protocols erode trust and create logistical challenges, further contributing to medication-related burden, poor adherence, and reduced quality of life, as demonstrated in the broader literature (21).

Geographic inequities exacerbate these issues, with specialist services concentrated in metropolitan areas. Limited capacity was also described for some States, such as Tasmania and South Australia. At a societal level, specialist shortages and differences in the geographic distribution of resources lead to inequities in timely diagnosis and ongoing care across the population (22). Beyond healthcare, narcolepsy's inconsistent recognition as a disabling condition restricts access to disability support (e.g., Centrelink payments and the National Disability Insurance Scheme (NDIS)). Danish registry studies confirm the substantial socioeconomic burden of Narcolepsy, including higher healthcare use, lower employment, and welfare reliance (23). Explicit policy inclusion of narcolepsy in disability frameworks may help reduce stigma, support earlier intervention, and improve quality of life.

From the analysis, a notable tension emerged around interacting with a society/culture that values economic production and other related cultural values. Societal stigma, reported by participants with comments from others as being "lazy," "pathetic," and "weak", stem from low public and professional awareness and understanding of narcolepsy as a neurological disorder. Inaccurate media portrayals can perpetuate misconceptions and harm the quality of life for PwN (24) (9). Targeted campaigns have reduced diagnostic delays and stigma in other contexts (e.g., Project Sleep (25) or the Italian Narcolepsy Association (27)). Australian public sleep health literacy initiatives, alongside advocacy for PBS expansion, recognition of narcolepsy in disability and employment legislation, could meaningfully address these societal determinants.

Community

At the community level, participants highlighted a lack of support groups available for people with narcolepsy, leaving many feeling isolated and without opportunity for validation. Prior evidence suggests that connecting with other peers is important to mitigate isolation and foster peer support by sharing practical coping strategies (26). Peer support has been shown to enhance self-management skills, quality of life, and psychological resilience, as individuals gain hope and validation through shared experience (27). Such connections can help alleviate the psychosocial

burden of living with a stigmatised and poorly understood condition. Community stigma and discrimination, including judgment and misunderstanding from employers, result in feelings of isolation and frustration. These community-level norms can impact symptom burden career protection and social participation. Workplace programs, implementation of workplace accommodations, and availability of peer-led initiatives may meaningfully enhance awareness, acceptance, and support for those living with Narcolepsy.

Organisational

At the organisational level, participants described a misalignment between what PwN sought from clinical consultations and what information and services they received, including inadequate follow-up and unclear referral pathways to healthcare resources and peer support groups. Clinical expertise in narcolepsy among healthcare professionals was experienced as highly variable across settings, likely reflecting limited organisational prioritisation in narcolepsy-specific training. Delayed diagnosis was often attributed to the limited clinician knowledge, particularly when symptoms overlapped with other conditions. These accounts are consistent with a 2021 survey of US healthcare professionals, indicating that narcolepsy remains one of the least understood chronic neurological conditions, with many clinicians expressing low confidence in recognising and managing it (10). Narcolepsy care was frequently perceived as narrowly focused on pharmacological symptom control, with limited attention to psychosocial functioning, occupational support, or comorbidities. These experiences underscore an urgent need for greater education and awareness of narcolepsy at the organisational level. Levers for improving early recognition and long-term management of narcolepsy at this level could include GP education (e.g., enhanced medical curricula, professional development), simple screening prompts, interdisciplinary training, increased multidisciplinary input, and greater emphasis on holistic care (e.g., integrated models incorporating psychology, occupational therapy, and peer support).

Interpersonal

At the interpersonal level, participants described stigmatising interactions across relationships that affected psychosocial outcomes, quality of life, and erosion of trust in healthcare providers. Participants reported that family and friends misunderstood them and were not as supportive as needed, leading to feelings of invalidation and hopelessness. Relational experiences with specialists and other clinicians that were also reported by some participants as dismissive and invalidating. These relational factors can delay diagnosis, undermine treatment, and leave people with narcolepsy feeling unseen, which is consistent with prior research (9). At this level, targeted awareness and communication training for clinicians, shared decision-making tools, and family-based interventions may improve outcomes for people with narcolepsy.

Individual

In the socioecological conceptualisation, individual-level factors refer to personal characteristics of an individual that influence their care-seeking behaviours and the daily impacts of living with narcolepsy. Notably, respondents identified relatively few individual-level factors as affecting care and management outcomes. Rather, participants emphasised broader social and systems/policy barriers, suggesting that these factors outweigh individual-level factors in terms of their challenges. This contrasts with the current dominant medical model, which focuses on symptom management and interventions focused on the individual level. These findings suggest

that a reorientation of care models toward addressing structural and relational factors, alongside clinical management, may better address the concerns of people living with narcolepsy.

Downstream life-course consequences of narcolepsy

In our socioecological conceptualisation, we situate the personal impacts of narcolepsy (daily limitations, parenting challenges/family dynamics, working pressure, financial instability, mental health problems, and relationship impacts) as downstream consequences of interacting individual, interpersonal, organisational, community and policy-level contexts. These findings reveal the profound disruptions to daily functioning among people with narcolepsy, which emerge and accumulate from multilevel determinants over time. These experiences align with prior evidence of the extensive multi-domain burden of narcolepsy beyond excessive sleepiness symptoms alone (28).

Notably, challenges faced by women during the perinatal period were highlighted, including limited clinical guidance on medication safety and unmanaged symptoms during pregnancy and early parenting. This highlights a critical gap in gender-sensitive research and care (29, 30), warranting targeted perinatal pathways at organisational and policy levels. Workplace functioning emerged as another key area of impairment, particularly in high-demand environments, where cognitive difficulties and fatigue impacted productivity and performance, with spillover impacts to social engagement and caregiving roles, likely contributing to elevated depression rates reported in narcolepsy (31). These findings highlight the importance of workplace accommodations and psychosocial support as key levers at the intersection of multiple levels. Financial insecurity was also pervasive in participant accounts, reflecting systemic barriers to employment, disability support, and care costs. This reflects evidence of the profound direct and indirect economic costs of narcolepsy (32), reinforcing the need for policy reform to broaden workplace protections and disability support.

Mental health problems were deeply intertwined with these challenges. Reports of depression, anxiety, emotional exhaustion, and, in some cases, suicidal behaviour were described as linked to fatigue, isolation, and a lack of understanding from others. These findings align with evidence of psychiatric comorbidity in narcolepsy (8). The integration of routine screening for mental health, peer-based support, and multidisciplinary care models within narcolepsy management could mitigate effects, reduce isolation, and improve quality of life. At the same time, participants also reflected on the impact of narcolepsy on their relationships. These interpersonal dynamics were noted to strain relationships and heighten isolation. Collectively, findings from this study highlight how multi-level barriers interact to produce profound personal impacts across a range of domains for people living with narcolepsy.

Strengths and limitations.

A key strength of this study was collaboration with patient organisations, which strengthened recruitment by enabling direct engagement with the narcolepsy community and enhancing the relevance of the findings. However, this strategy may have introduced a sampling bias, favouring individuals who are digitally engaged or involved in advocacy. The sample also relied on self-reported diagnoses and included a higher proportion of female respondents, which may limit generalisability. Furthermore, data were derived from open-response survey questions rather than interviews, thereby reducing opportunities for rapport-building and elaboration. This design also

constrained our ability to determine representativeness across diverse backgrounds. Broader and more inclusive recruitment strategies are recommended for future research. Notably, this study offered two novel contributions: first, a fine- grained mapping of advice given and withheld during care interactions; and second, an explicit multilevel framing or barriers and challenges. Unlike traditional biomedical approaches that emphasise symptom experience, this framing emphasises how systemic, structural and relational factors can influence experiences and outcomes of people with narcolepsy.

Conclusions

This study demonstrates that people living with narcolepsy in Australia face multilevel and multi-domain challenges, including restrictive medication access, limited public and clinician awareness, and insufficient social and psychosocial support. By applying a socioecological framework, these findings challenge prevailing individualised narratives of narcolepsy and highlight multi-level levers for interventions that extend beyond symptom management. Addressing these gaps will require systemic reforms to reduce stigma, improve diagnostic timeliness, and promote integrated, person-centred care. The inferred priorities identified from lived experience narratives on the challenges and care experiences of living with narcolepsy highlight demand for more accessible, coordinated care across the diagnosis and management pathway that is easily navigable. Examples of such resources could include self-management support tools, clinician decision-support tools, workplace guidelines, and national awareness campaigns to support those directly affected by narcolepsy. Future research should co-design and rigorously evaluate multilevel interventions that incorporate the perspectives of people living with narcolepsy, targeting interpersonal, organisational, and policy-level determinants of care and management.

Acknowledgements

We acknowledge the contributions of author MC, who designed and distributed the survey to collect information on frequently asked questions, complaints, and challenges reported by caregivers and PwN. We also acknowledge the contributions of Hypersomnolence Australia for recruitment and distribution of the survey.

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