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Identifying and integrating consumer-prioritised topics and outcomes in clinical practice guidelines on managing kidney stones

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on behalf of the Caring for Australian and New ZealandeRs with Kidney Impairment (CARI) Guidelines Steering Committee[1*]

Abstract

Aim The prevention and management of recurrent kidney stones can be challenging and requires patients to modify their diet and daily rountines that impact their quality of life. Our study aims to describe the process of integrating consumer-prioritised topics and outcomes in guidelines on kidney stones to ensure patient relevance.

Methods Two workshops were convened in Aotearoa New Zealand with people with kidney stones invited to identify topics and outcomes for inclusion in the guidelines. Flipcharts and transcripts were analysed thematically to identify the reasons for participants' choices.

Results The topics identified by the twenty-eight participants included education on nutrition, better diagnosis, and individualised nutritional and pharmacological management. Pain, equity of access, anxiety about recurrence, and life participation were identified as important outcomes to be included. Four themes (and subthemes) underpinning priorities were: unresolvable debilitating pain (complexity of exctruciating acute episodic pain, inadequacy of pain relief medication, frustrated by stigma associated with opioids), dissatisfied at delayed access to care (prolonged difficulties in diagnosis, struggling to obtain individualised care), inadequate knowledge to enable self-management (insufficient information on kidney stones, conflicting nutrition advice, cultural deficit), and limiting life participation (restricting life choices, psychological burden of kidney stones).

Conclusions Participants identified topics that would support symptom management to improve quality of life and reduce the burden on families. Guidelines should provide essential, consistent and clear guidance, particularly on nutrition, to support self-management. Incoporating consumer priorities in guidelines can help to support decision-making and patient-centred care in kidney stones.

Keywords Kidney stones, Nephrolithiasis, Consumer involvement, Clinical practice guidelines, Patient-centred care, Nutrition

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Background

Kidney stones affect about 10% of the adult population [1, 2], and the incidence of kidney stones is increasing worldwide [3–6]. About 35% to 50% of people with kidney stones experience recurrence within five years [7]. Kidney stones cause debilitating symptoms, such as vomiting, nausea and pain. Emergency departments are burdened by the presentation of acute pain due to kidney stones, with one of the highest rates of representation at these services [8]. People with kidney stones have reported impaired quality of life [9, 10], with kidney stones recurrence causing anxiety and low mood [11]. Kidney stones can also limit life participation through impacts on the ability to work, leading to financial concerns and family impacts [12].

Whilst there are guidelines on the management of kidney stones [13–20], they may not address the areas that are relevant to people who have had kidney stones. Integrating patient perspectives and priorities in clinical practice guidelines is now widely advocated to ensure they are meaningful and relevant to patients [21–24]. The Caring for Australians and New ZealandeRs with kidney Impairment (CARI) Guidelines have also demonstrated that the involvement of people with lived experience of disease broadens the scope of clinical practice guidelines and enhances their relevance and translation [25].

We convened workshops to identify people with kidney stones perspectives on topics and outcomes to integrate into the CARI Guidelines update on kidney stones management. We also aimed to describe reasons for their selection of topics and outcomes and discuss how their input was integrated by the guideline Working Group into the guideline.

Methods

Context

CARI Guidelines facilitate the development and implementation of clinical practice guidelines for chronic kidney disease in Australia and New Zealand. A Working Group of five nephrologists, one urologist, one clinical biochemist, two consumers and one kidney-specialised dietitian was convened to discuss the update of a guideline for managing kidney stones [14–20]. In the initial Working Group meeting, preliminary topics were identified, with topics prioritised (determined via feasibility), for inclusion in the guideline update using the Population, Intervention/Exposure, Comparator, Outcomes, Methodology (PI/ECOM) framework. To help ensure that the inclusion of topics and recommendations aligned with what is relevant and meaningful to consumers, two half-day workshops were convened in Aotearoa New Zealand, on May 2021, in Auckland and Whangārei. These workshops aimed to elicit patient and caregiver perspectives about topics and outcomes for inclusion in the guideline update. The study has been reported according to the consolidated criteria for reporting qualitative research [26].

Participants and recruitment

People with kidney stones were eligible if they were aged 18 years or over, spoke English, had experienced at least one episode of kidney stones, or were a caregiver of a person who had experienced kidney stones. Assisted by three New Zealand-based Working Group members, participants were recruited from kidney stones clinics based at New Zealand tertiary hospitals, across two locations (Auckland, a major city in the north of New Zealand's North Island; Whangārei a rural centre in the Northland region of the North Island). After expressing interest, particpants received a patient information sheet from the Working Group members and provided informed consent to participate. A purposive sampling strategy was applied to obtain a wide range of demographic and clinical characteristics (i.e., type of kidney stone). Participants were reimbursed with an hourly sitting fee as well as any travel-related costs (i.e., petrol, parking). Ethics approval was granted by The University of Sydney's Ethics Committee (2020/724). The project was also approved as low risk by the Auckland District Health Board after a review of the University of Sydney's ethics approval.

Data collection

Workshop format

Both workshops were convened in a centrally located venue external to the hospital setting to develop rapport and support participants in sharing their experiences. Each workshop commenced a welcome according to local culture (Karakia) and refreshments and lunch provided to acknowledge the participants valuable contribution. The workshop had a 30-minute introduction session, during which participants were provided with an overview and explanation of clinical practice guidelines, their purpose, the integrated guideline development process (Fig. 1), and the CARI Guideline's history. The participants were then split into focus groups of approximately six to eight people. The focus groups were facilitated by the CARI Guidelines staff and a consumer Working Group member (DJT, BC, AY, IW). The Auckland workshop had two focus groups (6–8 participants each), each with two facilitators, and for the Whangārei workshop, participants had three smaller focus groups (6–8 participants each), with one facilitator each.

The question guide was developed based on previous CARI Guidelines consumer involvement workshops [27–30] and discussion amongst the authors. Whilst a detailed run-sheet (Table A1) was developed, the questions were semi-structured and used to stimulate discussion. The initial focus group discussions were

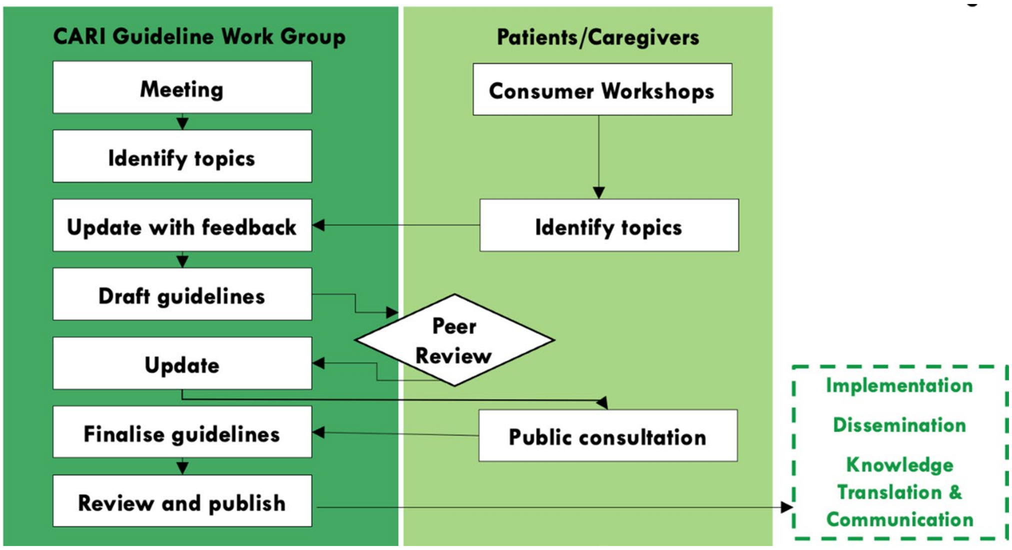

Fig. 1 CARI Guidelines guideline development process

surrounding participants' experiences of kidney stones–sharing initial and salient anecdotes. The second phase of the discussion focused on guideline topics, priorities, and outcomes. By linking these ideas to their lived experiences, facilitators guided participants to explain their choices and perspectives. A nominated participant from each focus group documented the discussions on a flip chart. During the final part of the workshop, the focus groups reconvened for a facilitated (DJT) plenary session, and a nominated participant presented a summary of key points to the broader group. All plenary and focus group discussions were digitally audio recorded and transcribed verbatim.

Data analysis

All transcripts and flip charts were entered into HyperRESEARCH (ResearchWare Inc., Randolph, MA, USA; Version 4.5.6). The transcripts and flipcharts were reviewed line by line to extract guideline topics and outcomes identified by the participants. The topics and subtopics identified were discussed amongst the facilitators (DJT, BC, IW, AY), and the revised list of topics was reported to the attendees for feedback. The primary coders (DJT, AY) inductively identified preliminary concepts relating to the beliefs, values, and attitudes for topic and outcome selection. These concepts were intially discussed by the research team (DJT, BC, IW, AY, AJ) and updated accordingly. The themes was then discussed with the guideline Working Group and the themes were revised to ensure the full breadth and depth of the data was captured in the analysis.

Table 1 Participant Characteristics (n = 28)

Characteristic	n	%
Participant Status		
Patient	28	100
Sex		
Male	19	68
Female	9	32
Age		
20–29	2	7
30–39	5	19
40–49	6	21
50–59	7	25
60–69	4	14
70–79	4	14
Ethnicity*		
Māori	3	11
Pasifika	1	4
Asian	3	11
European/Pākehā	21	75
Other/not reported	2	7
Location of residence		
Auckland	11	40
Whangarei	17	60

* participants were able to nominate multiple responses

Results

Participant characteristics

Twenty-eight adult participants attended the two workshops: 11 in Auckland and 17 in Whangārei. All were recurrent stone formers. No caregivers were present. Participant characteristics are shown in Table 1. Participant ages ranged from 23 to 79 years of age; 68% were (n = 19) male, and there was a mix of ethnicity with 21 participants identified as European/Pākehā descent, and seven participants as Māori.

Guideline topics and outcomes

In total, 36 topics were identified with 86% overlapping with topics identified by the guideline Working Group. The additional topics identified by the participants focused on education, self-management, and continuity of care. The workshop participants also identified relevant patient-important outcomes, pain reduction, psychological effects of recurrence, i.e., anxiety and life participation including the ability to maintain employment (Table 2). The participants also emphasised that guidelines should consider the impact on equity of access.

Themes

Four themes reflect the reasons for topic and outcome selection. Illustrative quotations for each theme are provided in Table 3, and the conceptual patterns and relationships among themes are shown in Fig. 2.

Unresolvable debilitating pain

Complexity of excruciating acute episodic pain

Participants described kidney stones-related pain as excruciating such that it impacted their ability to function. For some, the acute episodes of pain increased and decreased periodically. Some participants recounted presenting at emergency departments and being triaged as low priority as the pain had subsided and consequently had to wait a long time to be seen. Some participants in rural areas were concerned about taking pain medication at home as it may prevent them from driving to the emergency department if needed. Some were anxious about having to endure further acute episodes of pain. They reported avoiding travel to stay close to home, doctors, and their support networks to ensure they could deal with future events. Participants reported that clinicians dismissed their reports of pain.

Inadequacy of pain relief medication

Participants were frustrated with being unable to receive adequate pain relief. They emphasised the need to improve protocols for prescribing and administering analgesics. Participants understood the need for judicious use of potentially addictive pain medications. However, they wanted earlier access to medications that had worked previously during their acute pain episodes. Some participants conveyed that the opioid medications prescribed to manage the chronic ache of kidney stones-related pain impaired their ability to function.

> *There's no point in having like Tramadol and Sevredol [opioids], and be like, "Yeah, I'm going to function." You might as well just fall on your face. You're not there… it just wipes you completely off the earth. (Male, 20–29 years old)*

Some reported finding work that did not involve manual labour or turning down extra shifts or jobs to avoid having to depend on long-term pain medication.

Frustrated by stigma associated with opioids

Some participants reported that clinicians in emergency departments assumed they were "addicts" when seeking pain relief - *"I get treated as if you're some sort of addict going in…"* (Male, 40–49 years old). To avoid the stigma associated with opioids, some opted to use complementary and alternative therapies such as traditional Māori medicine (Rongoā) and massage or marijuana to relieve pain.

Dissatisifed at delayed access to care

Prolonged difficulties in diagnosis

Participants were distressed because of a delayed diagnosis of kidney stones - *"I actually struggled to get care initially. It was really hard to get anyone to help me. I couldn't get any care."* (Female, 60–69 years old). Some explained they had presented to emergency departments multiple times with excruciating pain felt often ignored by clinicians and were commonly dismissed after the stone had passed without consideration of referral for metabolic workup and assessment to receiving an underlying metabolic cause of their kidney stones.

Some believed clinicians needed to be able to identify risk factors for kidney stones for a more timely and accurate diagnosis. However, they emphasised the need for guidelines to include identification of those not considered conventionally to be at risk of kidney stones. Participants who didn't fit the "typical" kidney stones profile (i.e. Caucasian, male, older age) described clinicians often not considering kidney stones a possibility– *"… A few doctors said to me, 'I think you might have kidney stones, but you just don't fit the demographic'…"* (Female, 20–29 years old)

For some, the initial onset of acute pain occurring during adolescence resulted in clinicians dismissing their pain and attributing the pain to "female issues" [menstrual symptoms] or "urinary tract infections".

Struggling to obtain individualised care

Participants felt that the management strategy for preventing stone recurrence was generic and did not account for their individual context and underlying diagnosis. They suggested that stone analysis and metabolic evaluation should be completed so clinicians could tailor the management strategy according to their specific types of kidney stone. They believed that evaluating the metabolic cause and the stone type was not common practice and was often only offered after stone removal.

> *It's the process of going through and analysing why the stones came about. In my case, it's only after*

Table 2 Guideline topics and outcomes for kidney stones identified by consumers and the Working group

Guideline subtopic	Identified by consumers	Identified by Working Group	Comments from consumers workshop
Epidemiology			
Incidence		✓	
Prevalence	✓	✓	• Equity issues– gender and ethnicity differences need to be identified by the guidelines
Clinical diagnosis and risk factors			
Clinical diagnosis	✓	✓	• Timely diagnosis and focus • Focus on out-of-pocket costs and impact on mental health and quality of life
Risk factors for kidney stones	✓	✓	• Risk factors to identify typical but not to miss atypical kidney stone formers
Referral pathways	✓		• Improving referral and continuity of care across specialties
Metabolic evaluation			
Stone analysis	✓	✓	• Stone typing to inform management to prevent stone recurrence • Outcomes to include self-management and knowledge gain
Basic and comprehensive metabolic evaluation	✓	✓	• Communication of tests results needs to be improved to inform self-management through dietary changes.
Risk of recurrence	✓	✓	• Identification of risk factors of stone recurrence to inform self-management of disease
Nutrition and lifestyle			
Role of dietetics	✓	✓	• Dietetics highlighted as important to support people to self-manage through nutrition and fluid intake. • Quality of life was identified as an important outcome when examining the impact dietetics has in kidney stone management
Fluid intake	✓	✓	• Frustration at delayed knowledge about fluid intake identified • Social and occupational impact of increased fluid intake identified as a patient-important outcome
Dietary patterns	✓	✓	• Confusion about diet was common among participants • Dietary patterns 'friendly' with kidney stones were commonly explored by participants • The costs, impact on quality of life and life participation of dietary patterns identified as patient important outcomes
Micronutrients– calcium, oxalate, potassium and vitamin D, sodium, magnesium, vitamin B6, creatinine	✓	✓	• The translation of micronutrients into everyday diet is required
Carbohydrates	✓	✓	
Fruit and vegetables (potential renal acid load)	✓	✓	
Fibre		✓	
Animal protein intake		✓	
Enteral feeds and parenteral feeds		✓	
Obesity	✓	✓	• Balance between weight reduction and reducing kidney stone recurrence was noted as challenging
Lifestyle - Occupation	✓	✓	• Kidney stones impact on work was a focus for participants • The impact treatment has on occupation identified as a patient important outcome
Lifestyle - Stimulants (Alcohol, caffeine, cigarette smoking)	✓	✓	
Lifestyle - Psychosocial– stress & anxiety	✓	✓	• Mental health impacts of kidney stones widely discussed and the need for psychological support services raised • Kidney stones impact on mental health and quality of life raised as important patient-important outcomes
Lifestyle - Exercise	✓	✓	• Clarity on the frequency and types of exercise suitable for kidney stone formers. • The impact of exercise on quality of life identified as a patient-important outcome

Table 2 (continued)

Guideline subtopic	Identified by consumers	Identified by Working Group	Comments from consumers workshop
Pharmacological management			
Specific therapies that increase stone incidence		✓	
Magnesium and potassium supplements	✓	✓	• Clarity on the evidence-based efficacy and safety of supplements identified • Supplements impact on kidney stone recurrence and quality of life identified as patient-important outcomes.
Oral vitamin D		✓	
Thiazide diuretics	✓	✓	• Kidney stone recurrence identified as patient-important outcome.
Citrate salts	✓	✓	• Tolerability of the liquid forms of citrate salts highlighted by participants • Kidney stone recurrence identified as patient-important outcome
Xanthine oxidase inhibitors		✓	
Thiol drugs (penicillamine, tiopronin)		✓	
Alternative medicine - Rongoa Māori/ traditional medicine	✓		• Incorporation of traditional medicines and massage in kidney stone management raised
Pain management			
Pharmacological and non-pharmcological therapeutics for acute pain from kidney stones	✓	✓	• Pain management was experienced by most participants, frustration often conveyed about inadequate pain management • Stigma associated with pain management, with gender biases and ethic biases often experienced • Pains impact on life participation particularly employment, mental health, addiction identified as a patient-important outcomes
Surgery			
Type of surgery for kidney stones	✓	✓	• Improved communication on surgical options and potential harms of surgery were identified • Better post-surgery follow-up required
Education			
Patient education	✓		• Improved patient-friendly education resources on kidney stones were desired • Knowledge gain and changes in self-management behaviour identified as patient-important outcomes
Self-management	✓		• Self-management to recognise signs and symptoms of kidney stone recurrence • Pain reduction and improved life participation identified as patient-important outcomes
Healthcare provider education	✓		• Improved patient experience– less repetition, timely access to appropriate identified as patient-important outcomes
Models of care			
Multidisciplinary care in kidney stones	✓		• Shared clinics with a focus on continuity of care • Technology to improve sharing of medical history between providers • Improved care in emergency departments • Patient experience, kidney stone recurrence, pain management, costs and quality of life identified as patient-important outcomes

> *they did the surgery and took it out they could identify them as calcium oxalate stones... (Male, 60–69 years old, Auckland)*

Participants struggled to find the 'right' people to tailor treatment to prevent kidney stones. They stated that referral pathways across medical specialities and dietetics were vital to ensure individualised nutrition and pharmacological therapy to prevent the recurrence of kidney stones. Some participants noted the poor communication between public and private providers and across healthcare disciplines. For example, a participant stated that urologists never passed on information after their stone removal procedures to other medical specialists. Particularly back to primary care, which limited the ability to make changes to their diet and lifestyle to self-manage and prevent reoccurring kidney stones.

Inadequate knowledge to enable self-management

Insufficient information on kidney stones

Some were unaware that kidney stones could reoccur and felt unprepared for future acute episodes of stones. On

Table 3 Illustrative quotations

Theme	Illustrative quotations
Unsolvable debilitating pain	
Complexity of excruciating acute episodic pain	"The way I found it is your struggle to sit, you struggle to stand, you struggle to lie down, whether it's on your back, your side, and it does not matter. It's excruciating." (Male, 50–59 years old) "When it comes to pain, it's getting treatment for that pain. Because by the time you get somewhere, the pain might've subsided. Then, they send you home and the pain hurts again…" (Male, 60–69 years old) "They send you on your merry way and then you're not fine again…" (Female, 40–49 years old) "If you need [opiods] to get on top of the pain at home, but then the problem is, is then you can't drive. So then it's the problem of do I wait 45 minutes for an ambulance, crying in pain, or do I take the pain relief at home." (Male, 20–29 years old) "… kidney stone pain comes in waves. So one minute you're in agony and then the next minute you're kind of fine again. And then, you're terrified though of the next wave coming." (Female, 40–49 years old)
Inadequacy of pain relief medication	"It's the side effects and things like that… The addictions that I've had to pharmaceutical pain relief is horrendous. I'm in my 20s and I've been more addicted to them than other alternative pain relief" (Male, 20–29 years old) "If you go to emergency, they start you off on probably taking some paracetamol. You're off taking paracetamol and slowly building up to the better drugs, I suppose. But most of the stuff they start you off with doesn't touch it." (Male, 40–49 years old) "I'm an apprentice fabricator, heavy fabricator. Just take codeine and Tramadol. Go back to work as a heavy fab, welding structural steel, we're welding on trucks, we're doing custom truck jobs, I'm just going to go, hang on, I'm getting sore. I'll just have some Tramadol, have some codeine, and then… I'll cut my arm off." (Male, 20–29 years old) "So, I'm fortunate enough that I'm able to do it. I've rearranged my life so that I've tried to cut a whole bunch of stress out." (Male, 30–39 years old)
Frustrated at stigma associated with opioids	"You're an addict. You're a drug addict." (Male, 50–59 years old) "I wanted the pain relief… give me pain relief. And then I was Māori, requesting pain relief, wanting *more* pain relief… *still* asking for more pain relief. And so then I wasn't getting much care at all, because I was just totally judged…"(Female, 40–49 years old) "First thing I said, when I went to the hospital. Right. I need 5 ml of morphine to stabelise me, I am a big boy. You are a drug addict now?" (Male, 60–69 years old) "So through my childhood, definitely used Rongoā [Māori medicine], and mirimiri [massage] to help relieve pains." (Female, 30–39 years old)
Dissatisifed at delayed access to care	
Prolonged difficultes in diagnosis	"The first few times that I had it, I didn't know what it was. And it never really got found out, because they pretty much sent me away." (Male, 50–59 years old) "I think I had several of them before I ever found out. So I went to the hospital a few times. Just severe pain. And because it was in Emergency, you don't look like you're a problem. So we're sort of pushed aside while they're dealing with people who are bleeding to death, I suppose. Then by the time you actually got seen, it had passed." (Male, 40–49 years old, Whangārei) "Tell them [clinicians] to listen to us. Listen. Listen to us when we speak, don't just hear us, but you need to listen to us so that you know what's going on…" (Male, 50–59 years old) "Because I didn't fit the criteria, they were like, "You don't have any of the characteristics… you're not a 60 year old man…" (Female, 20–29 years old) "The urologist is only interested in treating the stone, not preventing it…" (Male, 40–49 years old) "They already had a diagnosis of a kidney stone…. And I already had a septicaemia once before with a kidney stone. I said to them, "I'm terrified to go home in case I get septicaemia again and get as sick as I did." [They said] "That was rare, very unlikely to happen again." And literally, got sent on my way. So it was being dismissed and hello, I got septicaemia again." (Female, 60–69 years old)
Struggling to obtain individualised care	"In my case, it's only after they did the surgery and took it out, they could actually analyse it as calcium oxalate stones. And the doctor, she's been very good over the last year, trying to figure out why do the calcium oxalate stones get created, looking at every level which had spiked, and some levels which had spike two years, a year before the surgery." (Male, 60–69 years old) "[One of] the main things for me… is around the type of kidney stone… there is different management for some different types and that's quite a big thing that I've come across in my care…" (Female, 20–29 years old) "It was only when the new doctor took over and during the process of checking everything and she started analysing, so she said, "All right, have you seen a dietitian?" I said, "No." And she had recommended six months earlier, but nothing happened… I hadn't even bothered about it, I didn't realise how important it can be."" (Male, 60–69 years old) "[the dietitian] was a godsend because she gave me a whole lot of information so that I could help myself. I could read easily what was good for me and what wasn't. So now, there's a whole list of things that I do eat and a whole lot of things that I don't eat. I'm careful about my salt. I drink a lot of water…" (Female, 60–69 years old) "He [Primary Care Doctor] is happy to pass that information to the specialist, but they are not interested in passing information back the other way…" (Male, 40–49 years old) "I don't think the [public hospital] doctor knew how to manage it… they only sent me for an x-ray, no CT scan… [my private doctor said] "That was their first mistake. They didn't follow the guidelines." (Female, 40–49 years old) "[I've] bypassed another hospital and come straight here, even though that one's closer… because you're not getting the same treatment…" (Male, 40–49 years old)

Table 3 (continued)

Theme	Illustrative quotations
Inadequate knowledge to enable self-management	
Insufficient information on kidney stones	"They need to prepare you that you will have pain again. These are the things you must tell the people so that they understand what the issue is." (Male, 60–69 years old) "It's just the awareness of making people understand what's required, what's going to happen…" (Male, 60–69 years old) "We understand that health services are under pressure. But we still need help. And we still need to be advised what we can do to help ourselves, and in English that we can understand…" (Female, 50–59 years old) "Patients are not told exactly what's going to happen in the surgery. What's going to happen? What's the care? Where are the stents going to be? How long will you be in hospital, and what can you experience?" (Male, 60–69 years old)
Conflicting nutrition advice	"… you've got another barrage of sometimes the same information… sometimes different…" (Female, 50–59 years old) "You go to one doctor, and they tell you one thing; you go to the specialist, and they tell you something else…" (Female, 60–69 years old) "The diet thing always gets me because you see different doctors and you ask them, is it food related? Half of them say, "no, it's got nothing to do with food, it's hereditary, it's part of you… Then another one will say, Oh, it's 10% diet." (Male, 50–59 years old) "… you see all these ads where rice isn't good for you, potatoes or certain potatoes aren't good for you. Tomatoes aren't good for you… You start naming. So what the hell am I supposed to eat?" (Male, 60–69 years old) "[a hospital dietitian] gave me a printout that she'd found of some medical college had done a study on what was good food for kidney stones, and what wasn't. It was a recognised site… She printed it out for me, which was fantastic. So then I could just take it home and absorb it, myself." (Female, 50–59 years old)
Cultural deficit	"You get to a point where you're willing to try anything because you get them that often. One year I've been in hospital about seven times, so you just get to a point where you've had enough…" (Male, 40–49 years old) "I've also tried some natural things that I found online. It's what they have in the Amazon… it's known as Stone Breaker." (Male, 40–49 years old) "So through my childhood, definitely used Rongoā [Māori medicine], and mirimiri [massage] to help relieve pains." (Female, 30–39 years old)
Limiting life participation	
Restricting life choices	"The inconvenience on our families… work costs, travel costs… my partner took six months off work…" (Female, 30–39 years old) "It's quite hard up here [in Whangārei]. Whereas if you go to Auckland Hospital, they make it known that before you even get to Auckland Hospital, that a family can go here and stay. If they've got no money, they can go to whanau house, if they've got a little bit of money, they can just go across the road. And it's 30 bucks a night to stay in a five star. And there is places for food and meals. You get a whole lot of information before you leave Whangarei Hospital about how the family can manage in Auckland. But when the family's in Whangārei, there's nothing… no options…" (Female, 40–49 years old) "I couldn't go back [to my welding job]… with early signs of kidney failure at 22… that's why I ended up walking away. I mean, I didn't really have an option. It was either that or I get plugged into a dialysis machine." (Male, 20–29 years old)
Psychological burden of kidney stones	"That's part of the biggest factors for kidney stones. Stress." (Male, 60–69 years old) "The illness has enough stress on its own, and then you don't want to have additional stress from the system. You can do without that, because that's completely avoidable if the system works." (Male, 60–69 years old) "The mental health side of things, you tend to see, especially when I was young, how it impacts your family. And so I would tend to tell my mum, 'I'm okay, don't come in and see me in hospital'. I do it with my husband too now. He doesn't come into see me, he just drops me off and picks me up because you don't want them to take that on… that stress." (Female, 60–69 years old) [after a stone event] "You feel like you're going back to square one. You'll be absolutely fine, and you forget all about it… [until] you start the cycle again." (Male, 40–49 years old)

reflection, they would have adhered to therapy and made changes to their diet, including increased fluid intake, if they had known from the outset that stone recurrence was possible. They wanted guidelines to address patient education, specifically that patients should be informed that kidney stones could be a lifelong condition so patients could implement self-management strategies early. Participants reported a need to be actively involved in treatment decisions, such as long-term medications like citrate salts and thiazide diuretics. For example, they wanted clinicians to explain the benefits of citrate salts in reducing stone recurrence but also raise tolerability issues such as taste in a simple way to guide them in making informed decisions. Additionally, clinicians providing information on the likely outcomes of stone removal procedures would set expectations and remove feeling unprepared before their appointments.

Participants recognised the importance of promptly receiving 24-hour urine test results to facilitate self-monitoring and to support adherence to treatment and dietary changes to prevent kidney stone recurrence - *"We want someone to get back to us [after test results]… without actually having to go in there, or wait for your appointment in six or twelve months…"* (Female, 60–69 years old, Whangārei)

Conflicting nutrition advice

Participants felt they received conflicting information regarding nutrition and fluid intake and becoming frustrated when they followed the advice and changed their diet, only to be told they had been doing it wrong.

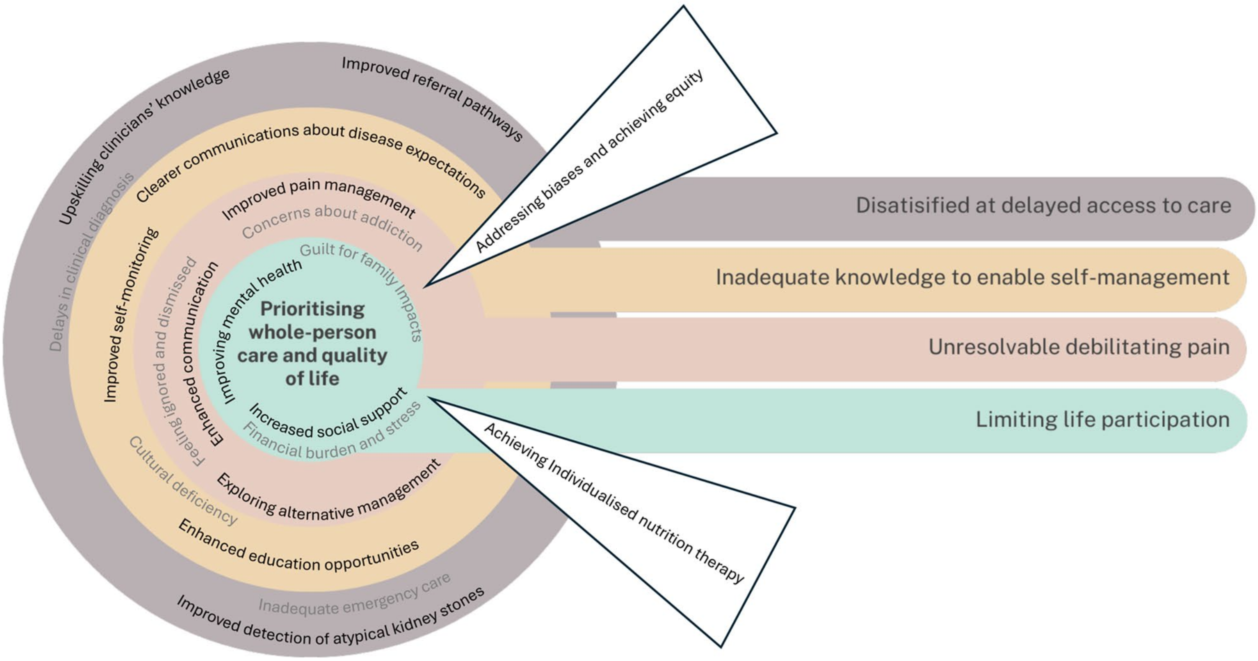

Fig. 2 Thematic schema. The five themes reflecting the reasons for prioritising guideline topics and outcomes are listed on the right-hand side with corresponding enclosing circles. The aspects targeted for inclusion and examination in the guidelines are highlighted within each of the thematic circles, with strength-based strategies highlighted in black. The participants recognised that crucial to achieving improved life participation through preventing recurring kidney stone events and their associated psychosocial impacts is the need for individualised nutrition therapy to support self-management. While a focus on addressing biases in provision of care was recognised as vital to ensure the benefits are experienced by all people with kidney stones, including those that do not fit the typical profile of kidney stones

Some participants recounted not receiving any nutritional guidance after their initial episode of kidney stone episode. - *"After my first one, I still did not realise that drinking water is so important… I wasn't told…"* (Male, 60–69 years old, Auckland)

Cultural deficit

Due to recurring kidney stone episodes, participants were willing to try anything, including complementary medicines to prevent stone recurrence. They wanted guidance on how traditional therapies (for example, mātauranga Māori) could complement Western medical treatments. Some reported that clinicians being dismissive towards these non-Western treatments, which strained the patient-provider relationship.

Participants emphasised the importance of access to appropriate food and fluids for kidney stone management. The participants from rural locations identified that access to food and drinking water could be variable. They identified ongoing dietitian support as vital to ensure the inclusion of cultural foods and consideration of the availability of local food.

Limiting life participation

Restricting life choices

Participants perceived that clinicians lacked an understanding how kidney stones impair the social and work opportunities. Some withdrew from social activities due to the inconvenience of constantly needing to use the bathroom due to their increased fluid intake – *"Wherever you go… the first thing… where's the toilet…? There's the social impacts, of "Where's the bathroom?"… I have to go to the bathroom every 20 minutes…"* (Male, 40–49 years old, Auckland)

Kidney stones limited some in their ability to work due to the increased fluid intake resulting in frequent bathroom visits being incompatible with some jobs, such as truck driving and school and early childhood teaching.

Participants who had families and children felt guilty that episodes of kidney stone and hospital visits also negatively restricted the career opportunities of their loved ones.

> *I didn't feel like I was much drama for my family, because I told them what's wrong, and you're in hospital for a few days, and then you're out and you're fine. But when my son presented in Year 11 at school, about what you're going to do in the future, he wanted to do a trade and work close to home, because he didn't want to go to university, because it was too far away, and mum goes to hospital lots… I didn't realise how it had affected him. (Female, 40–45 years old, Whangārei)*

Psychological burden of kidney stones

Participants described being *"rollercoaster of unknowns"*, which exacerbated feelings of anxiety and helplessness surrounding recurrence of kidney stones and the effectiveness of changes to their diets and behaviours. They felt anxious and stressed about the possibility of another episode of kidney stones and whether it would be severe enough to require a visit to the emergency department. Participants wanted increased support from diagnosis to treatment and follow-up so that people could come to accept their diagnosis and manage the distruption to their daily routine.

Discussion

The guideline topics and interventions important to people with kidney stones focussed on recognising and implementing the whole-person approach towards preventative healthcare to minimize stone recurrence. Prioritisation of education, providing tailored nutrition therapy by a dietitian experienced in kidney stone management, effective patient-clinician and multidisciplinary communication was demonstrated. The driving rationale behind these priorities was their need for consistency and clarification in both the care and information provided by clinicians, as well as the ability to gain and achieve better control through self-management and monitoring strategies. Alongside this, to improve life participation, patients required acknowledgement of the psychosocial impacts of kidney stone recurrence and the appropriate support for themselves and their families.

Previous qualitative studies have identified that kidney stones have a multidimensional impact with the desire for improved self-efficacy and challenges in maintaining employment reported [11, 12]. Our findings expand on previous studies by highlighting the desire for better prevention of recurrence through improved consistency of information and education, particularly on nutrition and sharing of information across health disciplines. It also highlights that guidelines must consider the psychosocial impacts of kidney stones. Furthermore, our study demonstrates the need for improved education, psychological support and models of care that have been outlined in other consumer involvement workshops [25, 27–30]. However, the kidney stones consumer workshops uncovered the breadth of insight and understanding into the reality of patients' pain experiences unique to kidney stones. Guidelines need to consider the type of pain medications provided, including how cultural bias may impact prescribing of analgesics for socially marginalised populations, how clinicians should approach and acknowledge the fluctuating nature of the pain episodes and the impact on employment. Further, conducting focus groups in Whangārei allowed for a perspective from regional areas, highlighting rich experiences unique to living outside a metropolitan city. Extremely valuable considerations of equity were raised, such as a focus on food security and discrimination of marginalised groups, which have not been highlighted in our previous work [27–30].

Despite purposive sampling of study participants to gather a wide range of experiences and perspectives, our study does have some potential limitations. CARI Guidelines produce guidelines for both Australia and New Zealand. Due to the COVID-19 pandemic enforced lockdowns focus groups could not be conducted in Australia; thus, the transferability of the findings to other settings is uncertain. Further, non-English speaking patients were excluded from the study as there were no resources for interpretation. All participants had experiences of recurrent kidney stones. Whilst participants shared their experiences surrounding their first kidney stone episodes, their initial diagnosis, and perspectives regarding aspects that required improvement for diagnosis, it is uncertain whether additional suggestions for the guidelines would have been identified if people who had only experience one kidney stone were recruited in the study. Although qualitative studies have described marginal differences in the impact of disease, people with first-time kidney stones have limited concerns regarding employment and financial instability despite having a similar health-relative quality of life [12]. Furthermore, participants were sampled from two specialist kidney stone clinics, where they received a full metabolic work-up, nephrology review, and a tailored nutrition plan from a dietitian. This helped ensure a diverse sample in terms of demographics and clinical characteristics, including the type of kidney stone as reported by their treating physician. This recruitment strategy was intended to capture a wide range of perspectives. However, specific details regarding participants clinical profiles were not reported or recorded in the study. Additionally, the location of the kidney stone was not considered in our purposive sampling, which may have resulted the exclusion of certain experiences and perspectives.

Insights from critical stakeholders are missing, we acknowledge that no caregivers were involved, who could provided additional perspectives to inform the guidelines, such as selecting and preparation of foods for people with experiences of recurrent kidney stones. A contrast is also evident, clinicians may have an acute perception of kidney stones, focusing on each episode as it occurs [31], whereas patients place a high value on preventative measures that also allow them to have an active role in their care, aiming to minimise recurrence and adopt a strategic, long-term approach.

Although consumer involvement in research has become increasingly advocated [21–24], there is still no standardised approach for involving people with lived experience in the guideline development process. The methods highlighted in our organisational framework for consumer involvement in guidelines have been implemented for workshops previously conducted for other chronic kidney disease conditions [27–30] and are relatively effective and comprehensive for eliciting consumers' perspectives and insights on relevant priority topics and outcomes to be included in guidelines [25]. Despite various guidelines organisations involving consumers in guidelines, further research on the methods to evaluate the acceptability, feasibility and effectiveness of involvement strategies are required.

Conclusions

Kidney stones have a substantial psychosocial impact, with recurring kidney stone events resulting in limitations to life participation. However, the impacts may be effectively managed by empowering people with kidney stones with consistent and clear guidance on management, particularly nutrition, and acknowledging and addressing the wide-reaching effects of kidney stone related pain. The involvement of people with kidney stones in developing guidelines is critical to identifying the topics and outcomes to ensure their relevance, ultimately enhancing the quality of care and outcomes through supporting self-management of kidney stones.

Supplementary information

The online version contains supplementary material available at https://doi.org/10.1186/s12882-025-04160-w.

Supplementary Material 1

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The CARI Guidelines kidney stones Working Group includes DJT, IW, BJ, AJM, AM, LL, HCH, MJ. DJT, IW, BJ contributed to data collection, and DJT, IW, BJ, AJ, NSR to data analysis. DJ, IW, BJ, AJ wrote the manuscript text and prepared the figures and tables. DJ, AJ, MJ, HH and the CARI Guidelines Steering Committee (VL, ES, JB, HC, JC, VC, DF, MJ, RK, KL, CL, TN, CS, AV) were responsible for the design of the study. All authors reviewed and approved the manuscript.

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Data availability

The qualitative data generated and analysed during the current study are not publicly available as consent was provided by participants for use in the development of Australian and New Zealand clinical practice guidelines on managing kidney stones. Data may be available from the corresponding author on reasonable request with appropriate ethical approval required.

Declarations

Ethics approval and consent to participate

Ethics approval was granted by The University of Sydney's Ethics Committee (2020/724). The project was also approved as low risk by the Auckland District Health Board after a review of the University of Sydney's ethics approval.

Consent for publication

All participants provided informed consent to participate including the use of digital audio-recording and including the use of de-identified illstruative quotations in publications and associated presentations.

Authors information

Consumers involvement in this paper: IW is a person with lived experience of kidney stones who were involved in the data collection and data analysis and an author of this paper.

Competing interests

The authors declare no competing interests.

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