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ORIGINAL ARTICLE

Identifying strategies to improve life participation in children with chronic kidney disease: report from multinational SONG workshops

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ABSTRACT

Background. Children and young people with chronic kidney disease (CKD) experience impaired life participation, which has been identified as a critically important outcome for them. However, little remains known about strategies to improve life participation in children with CKD. The aim of this report was to identify strategies to improve life participation in children with CKD.

Methods. Four workshops [one in-person (English language) and three online (two English and one Spanish language)] were held with 79 patients and caregivers and 92 health professionals from 16 countries to discuss strategies and interventions to improve life participation in children with CKD. Transcripts were thematically analysed.

Results. Four themes were identified. 'Emphasizing life priorities' involved identifying and addressing patient values, focussing on freedom not restrictions, routinely assessing and monitoring life participation, and establishing and achieving goals. 'Minimizing treatment burden' included allowing flexibility in scheduling appointments, enabling better management of medications, and controlling debilitating side effects. 'Facilitating opportunities in community settings' encompassed providing ways to engage in education, encouraging engagement in social activities, promoting physical activity, and supporting work and career aspirations. 'Fortifying mental health, self-esteem, and motivation' included building confidence and addressing depression and anxiety.

Conclusion. Patients with CKD, caregivers, and health professionals identified a need for strategies for life participation to address the domains of personalized life priorities, minimizing treatment burden, facilitating access to opportunities, and strengthening wellbeing. Further development and evaluation of interventions that address these are needed to improve life participation in children with CKD.

Keywords: children, CKD, kidney disease, life participation, self-management

KEY LEARNING POINTS

What was known:

- Children and young people with chronic kidney disease (CKD) experience impaired life participation.
- Limited strategies are avaliable to improve life participation.

This study adds:

- Life participation in children with CKD can be improved by establishing strategies and interventions focussed on life priorities, minimizing treatment burden, facilitating access to opportunities, and strengthening wellbeing.
- There is a need for continued emphasis on multidisciplinary care coordination along with including education, community, and employment to improve life participation.

Potential impact:

- This study identifies strategies that can be implemented within clinical practice and incorporated into policies to ensure person-centred care.
- Implementing these strategies may improve life participation in children with CKD.

INTRODUCTION

Children and young people with chronic kidney disease (CKD) have a high risk of comorbidities, symptoms, and impaired physical and cognitive functioning. Many experience substantial disease and treatment burden involving management of complex care needs [1–3]. These burdens can collectively limit their ability to participate in activities that are meaningful and important to them [1, 2, 4, 5]. Life participation is defined as the ability to participate in activities that are meaningful and relevant to patients including but not limited to, leisure, family, work, and social activities [6]. The Standardised Outcomes in Nephrology-Kids (SONG-Kids) Initiative, which aims to establish core outcomes in CKD for children, has identified life participation as an outcome of critical importance for children [6, 7, 8].

Children with CKD experience impaired life participation in many aspects including school attendance, poorer academic outcomes and employment, low engagement in sports, dietary restrictions, travel limitations, and difficulties in establishing and maintaining social and intimate relationships, when compared with those without CKD [9–12, 13]. However, strategies and interventions to improve life participation for children and young people with CKD are lacking. A systematic review of patient-reported outcome measures (PROM) used to assess life participation in children with CKD identified only ten trials with interventions, of which more than half were pharmaceutical interventions with no trial identifying life participation as the primary outcome [14]. In addition, there is a lack of involvement of children with CKD and their families in developing strategies and interventions to address life participation. In this report of multinational workshops, we aimed to identify strategies to improve life participation among children with CKD, from the perspective of patients, caregivers, and health professionals. Ultimately, these strategies may be used to develop interventions that may be evaluated in a randomized controlled trial, with life participation as the primary outcome.

MATERIALS AND METHODS

Context and scope

Four SONG-Kids Life Participation consensus workshops were held to establish a core outcome measure for life participation and to identify strategies to improve life participation among those under 18 years with CKD (all stages), the latter the focus of this report. The first workshop was held in Adelaide (in-person, English-speaking) during the Australian and New Zealand Soci-

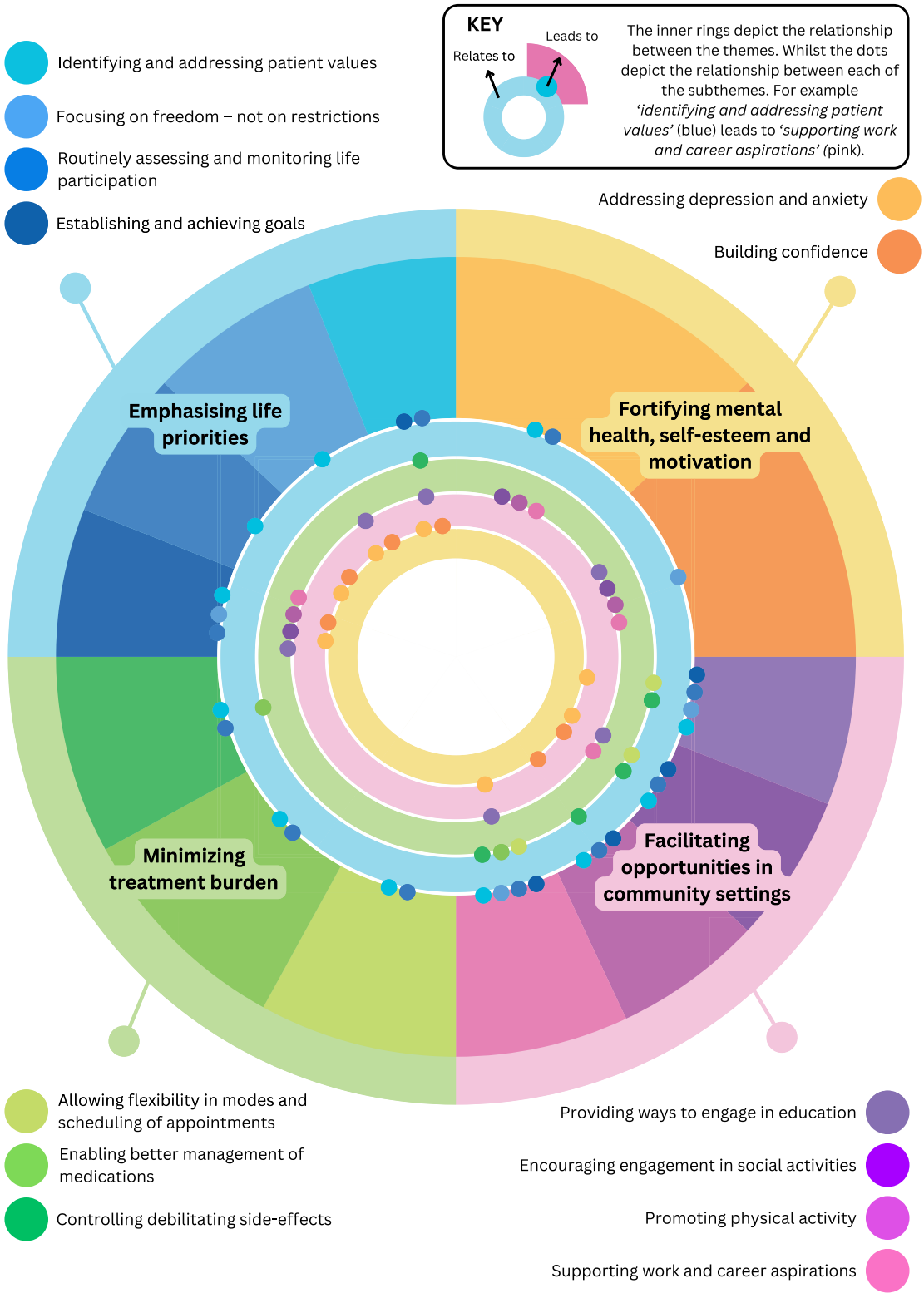

Figure 1: Thematic schema. The thematic schema depicts the relationships between the themes and subthemes.

ety of Nephrology's Annual Scientific Meeting on 3 September 2024. Online English-speaking workshops were held on 16 and 19 November 2024. One online Spanish-speaking workshop was held on 10 December 2024.

Attendees and contributors

Participants were invited to the workshop through the SONG network, and the networks of the SONG-Kids Life Participation Expert Working Group using a purposive sampling strategy. Patients, both children with CKD and young adults (older than 18 years) with childhood CKD, were invited to participate. Health professionals included those with clinical experience or research interest in children with CKD (e.g. paediatric nephrologists, trialists, and researchers), as well as those in advisory or leadership roles with key stakeholders including funding organizations (National Institutes of Health), regulatory agencies (Food and Drug Administration), professional societies (International Paediatric Nephrology Association), or registries. Supplementary File 1 outlines the full list of SONG-Kids Life Participation consensus workshop attendees.

In total, there were 171 participants including 79 patients and caregivers and 92 health professionals from 16 countries. In the first workshop (in-person, English-speaking), 42 participants from Australia ($n = 40$) and New Zealand ($n = 2$) attended: 14 patients/caregivers and 28 health professionals. For the second workshop (online, English-speaking), there were 20 participants: 5 patients/caregivers from Lithuania ($n = 4$) and Australia ($n = 1$); and 15 health professionals from Australia ($n = 7$), Singapore ($n = 2$), France ($n = 1$), India ($n = 1$), Lithuania ($n = 1$), South Africa ($n = 1$), South Korea ($n = 1$), and United States of America ($n = 1$)). The third workshop (online, English-speaking) involved 44 participants: 10 patients/caregivers from South Africa ($n = 5$) and Australia ($n = 4$); and 34 health professionals from the United States of America ($n = 14$), Australia ($n = 8$), Canada ($n = 3$), France ($n = 3$), South Africa ($n = 2$), Austria ($n = 1$), Germany ($n = 1$), New Zealand ($n = 1$), and China ($n = 1$)). The fourth workshop (online, Spanish-speaking) involved 85 participants: 54 patients/caregivers from Chile ($n = 39$), Mexico ($n = 11$), and Bolivia ($n = 4$); and 31 health professionals from Chile ($n = 17$), Australia ($n = 11$), and Mexico ($n = 3$)). Supplementary File 1 provides a full list of attendees.

Workshop programme and materials

All attendees were sent the workshop programme and background materials prior to the workshop. The workshop began with an overview of the SONG-Kids Initiative and the concept of life participation. Participants were allocated to breakout groups consisting of patients/caregivers and health professionals. The breakout groups were led by a facilitator and co-facilitator. Following discussion of the core outcome measure for life participation, participants were asked to suggest strategies or interventions to improve life participation in children with CKD. The question guide is provided in Supplementary File 2. Following breakout groups, all participants reconvened in the plenary session and each group provided a summary of their discussion.

The breakout discussions were audio-recorded and transcribed verbatim. The transcripts were coded and analysed in HyperRESEARCH software version 4.5.6. Author A.H. read the transcripts line-by-line to identify and code concepts to themes. The themes were reviewed by A.J. The preliminary workshop report was circulated to all investigators who were invited to provide feedback and additional comments, which, where appropriate, were integrated into the final manuscript.

Figure 2: Domains of life participation.

RESULTS

We identified four main themes which reflect the perspectives of children with CKD, their caregivers, and health professionals on strategies to improve life participation in children with CKD. These include emphasizing life priorities; minimizing treatment burden; facilitating opportunities in community settings; and fortifying mental health, self-esteem, and motivation. The themes and subthemes are described below, with supporting quotes for each subtheme provided in Table 1 . Figure 1 depicts the relationship between each of the themes and subthemes, whilst Figure 2 depicts the domains of life participation and examples.

Emphasizing life priorities

Identifying and addressing patient values

Participants believed health professionals needed to care for the whole child not just treat the illness by 'putting the person before the patient' and to help patients live 'life to the fullest' (Health professional, Canada). Participants highlighted the need to explore the individual values and priorities of patients—'What are those values? Doing a little bit of a needs assessment, what is important and then what gets in the way of that?' (Health professional, USA). They recommended focussing on the values of the patient when considering treatment, for example, 'It's the first question I ask patients, how are you going at home and are you doing what you can do? It's the most important part of our care, all the rest is just the extra stuff' (Health professional, Australia).

Focussing on freedom, not on restrictions

Patients stated that having CKD restricted their freedom—'(Others without kidney disease) can just be completely free and you really want to, but then you also have to think about your kidney the whole time' (Patient, South Africa). Participants

Table 1: Selected illustrative quotes to support each theme.

Emphasizing life priorities Identifying and addressing patient values	• 'It's got to be person-centred, prioritizing life participation is probably the first step' (Health professional, Australia). • 'As doctors, we do get so focused on medical stuff' (Health professional, Australia). • 'Frequent check-ins where we evaluate, what is most important, where do those values lie?' (Health professional, USA).
Focussing on freedom, not on restrictions	• 'How did you get around those barriers? Did you replace some activities that you might have liked to do that you couldn't?' (Health professional, Mexico). • 'Finding an alternate activity, you can't play sport anymore with your friends, but you can play PlayStation or play other kinds of sport that's not as intense' (Health professional, Australia). • 'You really want to (be completely free), but you also have to think about your kidney the whole time' (Patient, South Africa). • 'How do you still participate in life when you are in such a depressing environment in that sector of the hospital system' (Patient, Australia). • 'Patient and family education, the kid can do anything they want. We shouldn't restrict them' (Health professional, Singapore). • 'You can go to the party, but you still have restrictions' (Health professional, Australia).
Routinely assessing and monitoring life participation	• '(Asking about life participation routinely e.g. in clinical practice) could help other children my age with my condition or a similar condition' (Patient, South Africa). • 'Ask a set of questions, another post-transplant, after a year or 2 years where it is expected that there will be a different type of quality of life' (Caregiver, Chile). • '(Life participation is) key to what we do in terms of clinical practise and in research' (Health professional, Australia).
Establishing and achieving goals	• '(Goal setting can be) overwhelming, unachievable sometimes' (Health professional, Australia). • 'Hopefully create a little bit of a plan and working towards achieving (their goals)' (Health professional, Australia). • 'I'll go through those days where it's on my mind quite a lot think(ing) about longer term issues' (Caregiver, South Africa).
Minimizing treatment burden Allowing flexibility in modes and scheduling of appointments	• 'Electrical cuts last about two and a half hours and our machines only have a two-hour battery life, (which interpret treatment) so it really caused havoc with our families, things like that that are different to people living in lower-middle-income countries' (Health professional, South Africa). • '(Patients) have had to come off country (home) to live in Alice Springs, which is awful, they are further isolated' (Health professional, Australia). • 'You're managing the whole family, we try to make it easier, they have other child commitments at home, they may not be able to accompany the child to the appointment, it's perhaps virtual, get the blood work done locally' (Patient, Australia). • 'Given that medical care is in a different place and the social network is far away, area strongly impacts on the other activities related to having a normal social life, especially family life' (Caregiver, Chile). • 'After school, I might be busy with medical stuff. It's very restrictive' (Patient, Australia). • 'He does all the good stuff, but we still have to fit in the management of the disease' (Caregiver, South Africa). • 'It always depends on your schedule' (Health professional, China). • 'Changes in models of care for how you can enable people to participate in their life and still participate in their treatment?' (Health professional, Australia).

Table 1: Continued

Enabling better management of medications	• 'How do you reduce your pill burden? How many medicines are you taking?' (Health professional, South Africa). • 'It's like you go out and you buy a whole box of medications for one point (occasion and then not needed again)' (Health professional, Australia).
Controlling debilitating side effects	• 'Side effects from the medications can have long term effects such as brittle bones and osteoporosis. These need to be detected and managed early for example through exercise, medication, regular monitoring and education' (Caregiver, Australia). • 'Medication and treatment decisions need to consider more than a child's kidney health. What will be good for your whole body, not just what will be good for your kidneys?'' (Caregiver, Australia). • 'It would take so much worry off our plate if side effects of medications could be controlled. It would remove unnecessary discomfort, increase quality of life, and promote increased life participation if side effects could be controlled' (Patient, Australia). • 'Increased controlled side effects may increase adherence of treatment in patients' (Patient, Australia). • 'Preserving kidney function is important but the side effects of treatment can be so terrible that they prevent a child from functioning in life' (Caregiver, Australia). • 'It is hard to explain to a child that the things that are being done to make their kidneys healthy are the same things that make other parts of their body feel so unwell' (Caregiver, Australia).
Facilitating opportunities in community settings	
Providing ways to engage in education	• 'Homeschooling has helped him because while I'm sure he loves to be at school playing footy, (but) that's just not a possibility' (Patient, Australia). • '(Dialysis) was quite a physical strain, there were days when she didn't go to school, since she returned to school, it has been a considerable change after the transplant' (Caregiver, Chile). • 'It's not just about are you attending school but are you engaging and participating in it' (Health professional, Australia).
Encouraging engagement in social activities	• 'When you're interacting with friends about how much you're doing digitally, and in person?' (Caregiver, Australia). • 'A buddy system where you meet others in the same boat' (Health professional, South Africa). • 'Facebook groups or even within the clinic, another mum might want to chat with someone who else has got a child similar age or having that buddy network' (Health professional, Australia). • 'Being together at the table, sharing food, that is already a difficulty' (Health professional, Chile). • 'Adolescents or children hide their illness, their peers or friends do not know that they have kidney failure, so it is difficult for them to accept or trust their friends and open up about their condition' (Health professional, Chile). • 'It can make you feel a bit alienated from people' (Patient, South Africa). • 'Creating support, sometimes we think that we are the only people or around us' (Patient, Mexico),
Promoting physical activity	• 'To help physical activities, a very important (strategy and intervention) to improve quality your life' (Health professional, France). • 'Depending on your treatment, you modify how you participate' (Caregiver/health professional, Australia).

Table 1: Continued

Supporting work and career aspirations	• 'Provide a sense of normality to patients, with an occupation, patients are distracted to a certain extent from their CKD' (Patient, Australia). • 'Doing normal things like going to school or having a part-time job is so important for a child's sense of belonging and purpose' (Caregiver, Australia). • 'I felt my best when I could go to work, attend school, and do the fun, everyday things other kids my age were doing. Helped me feel 'normal'—like I wasn't just a sick person. I didn't stand out, and for once, I didn't feel like my illness defined me' (Patient, Australia). • 'Post-transplant, my daughter was able to go back to school and finish university, and live independently' (Caregiver, Australia). • 'Allow patients to work in industries that are suitable given their health limitations. Transplant patients might find it risky to work in a medical centre that has a high risk of infection' (Caregiver, Australia).
Fortifying mental health, self-esteem, and motivation Building confidence	• 'As doctors, (we) need to stop concentrating just on medical treatment, but getting young kids to live their best lives, it's hard to live with a chronic medical condition' (Health professional, South Africa). • 'Transplanted people are very careful not to get infected at school, if there are illnesses at school they do not go to school, (or) to a social gathering' (Caregiver, Bolivia). • 'My parents do not allow me to do this because I had the peritoneum catheter' (Caregiver, Chile).
Addressing depression and anxiety	• 'Activity of being able to decompress, to be able to vent' (Caregiver, Chile). • 'More psychological support for children with kidney disease' (Health professional, Chile). • 'You'd like to have more energy to do that versus that you've got this much capacity' (Health professional, Australia). • 'Supporting mental health is a priority. Kidney disease can impact every part of a child's life and help is needed to help them navigate that' (Caregiver, Australia). • 'When you have kidney disease, participating fully in life requires good mental and physical health' (Caregiver, Australia). • 'Not enough programs are in place to support mental health in patients with CKD. Gaps persist in the healthcare system with screening for mental health concerns and support' (Patient, Australia).

suggested that clinical consultations could place more emphasis on what patients could do and recommend 'tips', for example 'bring more water to sport' (Health professional, Singapore), rather than focussing on their restrictions. Health professionals suggested that patients should gauge what they are able to do based on their symptoms—'They should be restricting themselves according to their symptoms, not based on what parents want them to do' (Health professional, Singapore).

Routinely assessing and monitoring life participation

Participants expected that routine evaluation of life participation in clinical practice would prompt more attention and efforts to achieving life participation. Patients suggested that a 'doctor or social worker or anyone in the health team see their results (for life participation) and then come up with (strategies to help)' (Patient, Australia). Health professionals agreed this could help to identify and address barriers to life participation—'find out where the issues lie (e.g. through a) social worker' (Health professional, Australia).

Establishing and achieving goals

Some participants felt that goal-setting programmes related to life participation could encourage improved life participation—'(A) question for the future like what would you like to be, what your goals are? (Health professional, Australia). Health professionals felt that goal-setting could help to address 'facilitators and barriers to enabling someone's life participation' (Health professional, Australia). However, patients and health professionals agreed that for success it would need to be 'different than all the other goal-setting stuff in school' to ensure it is engaging, effective, and strong uptake of the program (Patient, Australia). Health professionals suggested opening 'a dialogue (about goals) in a way that feels more natural and accepted to the young person' (Health professional, Australia).

Minimizing treatment burden

Allowing flexibility in modes and scheduling of appointments

Patients and caregivers mentioned that travelling to attend appointments for follow-up and care disrupted life participation, particularly for those who resided a long distance from clinic or needed to relocate away from home—'families who are travelling 300 or 400 kilometres to come … how much time that takes out of a child's life … some of those kids are going to miss a day or maybe two days in doing these kinds of visits' (Caregiver, South Africa). Health professionals suggested that appointments should be scheduled to minimize the burden on patients or offer the option of outreach clinics, virtual appointments, or visits by clinicians for example to avoid missing school—'we just get the community nurse to go to the house or the school' (Health professional, Australia).

Enabling better management of medications

Patients and caregivers felt burdened by having to manage complex polypharmacy, which impaired life participation by disrupting routine, limiting social and lifestyle activities, and creating a 'sick' identity—'We've got half a pharmacy in our house' (Caregiver, Australia). Health professionals acknowledged the pill burden upon patients and their families as well as the complexities in managing medication—'One of my bugbears is doctors changing medications every clinic visit to get the blood tests perfectly right' (Health professional, New Zealand). Medication planning and follow-up reviews to support long-term management may help enable better management of medications to reduce overall treatment burden.

Controlling debilitating side effects

Side effects from treatment such as fatigue were debilitating and could prevent patients from engaging in their daily activities—'(the side effects) made me feel just as bad—if not worse—than the illness itself. I often had to miss out [on opportunities] because the side effects left me feeling completely drained' (Patient, Australia). Participants emphasized the need to be prepared for and to manage side effects to enable life participation—'Are there alternative treatments that might make a child feel less tired or make a child more likely to be able to go to school or hang out with friends?' (Caregiver, Australia). Caregivers suggested side effects could be 'managed early through exercise, medication, regular monitoring, and education' (Caregiver, Australia).

Facilitating opportunities in community settings

Providing ways to engage in education

Participants expressed that the symptoms of CKD and treatment burden made it difficult to attend school—'My most important activity is to focus on my studies more than anything else … I took a lot more medicine and I was younger so it made it difficult for me to do more activities unlike other children, I couldn't even go to school' (Patient, Chile). For some who attended school, it was difficult to engage in social activities or to concentrate on academic achievement and progression—'Sometimes you're completely missing out on school, but sometimes you're physically there, but still missing out' (Health professional, Australia). Participants suggested providing home and hospital school—'give the patient better devices (to enable distance learning) so that they can continue going to school' (Health professional, Mexico).

Encouraging engagement in social activities

Participants noted barriers to engaging in social activities including fear of infections, fatigue, scheduling, and food restrictions—'he rarely goes to birthdays because … he cannot eat what other children eat' (Caregiver, Chile). Providing an opportunity for patients and their families to strengthen social participation was emphasized and specific suggestions included holding events with other patients and families that are appropriately catered—'Programmes (when) you are around kids who are on food restrictions … (so) you are all eating the same stuff … you are also bonding as well' (Patient, Australia), fostering friendships outside of school settings as well as home-based programmes, and online modes of interacting with others—'scheduling a play date at a house if you're sick, that way you're not exposing yourself outside or a playground, the electronic space is a great idea' (Patient, Australia).

Promoting physical activity

Engaging in physical activity was difficult for children with CKD due to treatment, particularly dialysis—'hemodialysis did not allow us to play or do sports with a ball or things like that, be it basketball or soccer' (Patient, Mexico). Health professionals believed that opportunities to address physical activity would support life participation—'a small programme in our paediatric hospital with adapted physical activity and then we propose some individual sessions and then also some group sessions' (Health professional, France), and that these could be embedded in clinical settings by multidisciplinary teams—'play therapist, the OTs (occupational therapists), the social workers really engaged in facilitating the networking of the young people, them having fun together, having this life participation opportunity amongst the clinical setting' (Health professional, Australia).

Supporting work and career aspirations

Being able to work provided patients with a sense of normality and purpose—'I was so happy when I got my first job because all my friends have had jobs since they were 14' (Patient, Australia); and enables—'patients to prove themselves that they can achieve dreams and can promote self-esteem' (Patient, Australia). Strategies and interventions to support ability to work included flexible and suitable employment through policy and workplace accommodations, occupational therapy, training, career counselling, and peer support for guidance and connection.

Fortifying mental health, self-esteem, and motivation

Building confidence

Patients with CKD expressed that they were often discouraged and asked to refrain from certain activities, due to fear of infection, other risks to health, and reduced capacity. Patients noted that they lacked motivation to engage in life activities because they were 'in such a depressing environment in that sector of the hospital system' (Patient, Australia). Some patients lacked confidence to partake in certain activities (e.g. social activities)—'When you don't feel confident, you feel like you don't want to do anything' (Patient, Australia). Participants stated that constant encouragement from the patient's family, social networks and peers, and their clinicians, and dispelling myths would be helpful to positively reinforce their ability to participate in life activities. A caregiver also noted the need to strengthen their child's self-esteem—'I always encourage her and tell her that your best

is always good enough … it brings out a self-worth and her self-esteem' (Caregiver, South Africa).

Addressing depression and anxiety

Participants highlighted the need for programmes to support mental health—'someone who saw us psychologically, someone who could help us with the whole illness' (Caregiver, Chile) as improving mental health was expected to improve a child's capacity to participate in activities—'I've struggled with (mental health) ever since my diagnosis. I was lucky to have one main mental health professional who helped me manage my anxiety and depression—especially the social anxiety I felt when trying to do everyday things like go to school or hang out at parties. That support made a huge difference' (Patient, Australia). Additionally, caregivers shared that connecting their child with peers 'helps to manage anxiety, (and) uncertainty' (Caregiver, Lithuania).

DISCUSSION

Children with CKD, caregivers, and health professionals suggested that focussing on the child's priorities and freedoms, routinely assessing life participation, minimizing treatment and disease burden and providing opportunities and encouragement to engage in activities, and facilitating goal setting, could potentially help to improve life participation in children with CKD. They also emphasized the need for access to psychological and social support services to improve mental health, which could in turn foster motivation, confidence, and ability to participate in life activities. Results were consistent across English and Spanish language workshops as well as patients, caregivers, and health professionals.

Children with CKD encounter physical, psychological, and practical barriers to engaging in life activities [1, 2]. Debilitating symptoms, fear of infection, delayed independence, and sense of uncertainty have been identified as contributing to restrictions in their ability to engage in activities such as school, sport, and social activities [2]. Immersing in 'normal' activities, striving to reach potential, and finding enjoyment, have been identified as facilitators of life participation in children with CKD [2] and these challenges to life participation were also identified in our workshop. However, we identified unique challenges including treating the patient and not the person, restrictive routines due to scheduling and medications, difficulties achieving academic and career fulfilment, and self-esteem and mental health challenges.

Internationally recognized frameworks have highlighted the need to address life participation [15, 16]. The World Health Organization's International Classification of Functioning, Disability and Health Framework conceptualizes a person's function (or life participation) by identifying the relationship between health conditions, environmental, and personal factors [15]. The Living Well with Kidney Disease conceptual framework includes four areas to improve life participation including symptoms, life impacts, strengths-based approach, and clinical strategies [16]. The frameworks harness building resilience, support, self-management, social connections, and knowledge through strategies such as offering resources to manage stress, providing patient education, encouraging patients to ask questions, referring patients to allied health professionals, managing and preventing complications, and supporting communication of the patient's goals [15, 16]. The strategies and interventions identified in our workshop reflect many of the approaches suggested in these frameworks.

Table 2 outlines specific strategies aimed at improving life participation for children with CKD. Our workshop identified that enabling comprehensive person-focused care could be achieved by ascertaining the patient's priorities and goals using a strength-based approach that focuses on the child's abilities and assessing their life participation routinely in clinical practice. Minimizing the burden of treatment could be facilitated by scheduling appointments in a flexible manner, for example timing and location, in consideration of the patient's other responsibilities and addressing side effects. Broadening opportunities for education in school and home settings allows flexible engagement in academic learning. Programmes that address physical activity, social connection, and vocation, promote and enable life participation. Addressing mental wellbeing and thereby motivation to engage in activities may be facilitated through access to psychological services, as well as encouragement from those involved in the patient's care to participate in activities. Implementing these strategies will require a multidisciplinary approach to treatment involving allied health including psychologists and occupational therapists, and strong connections between educators and clinical teams to support a holistic and personalized approach.

The assessment of life participation remains a challenge as there is no standardized validated measure for life participation in children with CKD. The measures for life participation that have been used in children with CKD lack key aspects of validity, and most measures are contained in a broader construct such as quality of life, for example PedsQL, and are not specifically focused on life participation[14]. Through the SONG-Kids Initiative, there is ongoing work to develop and validate a core outcome measure for life participation, noting difficulties in capturing and measuring life participation with existing instruments. Previously, a Standardised Outcomes in Npehrology-Life Participation (SONG-LP) instrument, has been developed and validated in adults with kidney disease including kidney transplant recipients[17].

There is a need to co-design and evaluate interventions to improve life participation in children with CKD [14]. A systematic review of trials of interventions in adult kidney transplant recipients, including those that addressed exercise, diet and nutrition, and medication, found that the effect on life participation was uncertain with no trials reporting the outcome of life participation specifically [18]. There have been various nonmedical focused programmes, such as the Kidney BEAM digital health intervention for physical activity and the Kidney Optimal Health Program for mental health, that have been shown to potentially improve outcomes such as quality of life and psychological wellbeing [19, 20]. Goal-setting programmes may also be considered as this has been shown to align with life participation domains such as physical health, social engagement, and leisure in older patients with CKD [21]. Similar programmes could be adapted and developed for children with CKD.

In our workshop, we identified a broad range of strategies that could potentially improve life participation in children with CKD. Whilst we involved participants from many countries, we acknowledge that the transferability of these strategies beyond the countries and languages included in our workshop is uncertain. Further work to ascertain the influence of cultural perspectives on family relationship, and aspiration and goals related to life participation may be warranted. We acknowledge that other suggestions may not have been discussed in the workshop. For ex-

Table 2: Strategies to enable life participation in children with CKD.[a]

Strategy	Suggestions
Emphasizing life priorities	• Ascertain the individual priorities and values of patients with CKD as well as the facilitators and barriers (e.g. conduct goal-setting exercises or provide goal-setting programmes). • Focus on freedom rather than restrictions by providing suggestions to enable engagement (e.g. bring more water to sport). • Assess life participation routinely by using a validated PROM for life participation e.g. during appointments.
Minimizing treatment burden	• Ensure flexibility in scheduling appointments e.g. after school or work hours to ease managing multiple commitments. • Offer outreach clinicals/home visits. • Devise ways to minimize medication burden and polypharmacy (e.g. pill boxes and reminders). • Identify ways to prevent or reduce treatment side effects e.g. physical activity to manage fatigue.
Facilitating opportunities in community settings	• Deliver education in multiple settings including hospitals (e.g. hospital school) and home; and using online modes. • Provide social opportunities (e.g. programmes and camps for children with CKD, friendships at school, online, and controlled environment to minimize infection and other risks). • Facilitate access to physical activity programmes that are suitable for children with CKD. • Provide opportunities to connect with other patients and their families who share similar experiences (e.g. peer support groups and activities catering for diet restrictions). • Provide vocational/career counselling.
Fortifying mental health, self-esteem, and motivation	• Provide access to psychological services e.g. referral to a psychologist or provide strategies to manage anxiety and stress. • Dispel myths to balance risks and benefits in participating in activities e.g. by providing alternatives or suggesting small changes to activities rather than completely avoiding certain activities. • Encourage children to participate in activities by fostering positivity.

[a]As identified by patients with childhood CKD, caregivers, and health professionals.

ample, antidepressant medications prescribed for mental health which may also support life participation in children with CKD and their families.

Patients with childhood CKD, parents, and health professionals suggested that interventions that enable flexible access to care, support routine assessment of life participation, promote mental health to improve motivation to engage in activities, and programmes facilitating life participation may have potential to improve life participation in children with CKD. Whilst also acknowledging this goes beyond the scope of nephrology, and the subsequent need for a multidisciplinary coordination including education, community, and employment. There is a need to co-design and evaluate such interventions, which may ultimately help to strengthen patient-centred care and outcomes for children with CKD.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

AUTHORS' CONTRIBUTIONS

A.H. analysed the data and drafted the manuscript. A.H. and A.J. conceived the study. A.H., A.J., A.M.G., A.v.Z., C.G., S.C., D.C., A.D., J.R.S., J.C., S.K., K.M., C.O., A.Re., B.S., N.S.R., A.S., R.W., M.M., N.A., X.A.C., P.D.L.C., G.A.G.L., C.G., N.G.A., M.M., V.P., L.Re., L.Ro., A.Ro., A.S., L.T., and A.V. were involved in data collection (as facilitators or co-facilitators). All authors reviewed and edited the manuscript.

SUPPLEMENTARY DATA

Supplementary material are available at *Nephrology Dialysis Transplantation* online.

CONFLICT OF INTEREST STATEMENT

The authors report no conflicts of interest as well as financial interest.

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