

BMJ Open

BMJ Open is committed to open peer review. As part of this commitment we make the peer review history of every article we publish publicly available.

When an article is published we post the peer reviewers' comments and the authors' responses online. We also post the versions of the paper that were used during peer review. These are the versions that the peer review comments apply to.

The versions of the paper that follow are the versions that were submitted during the peer review process. They are not the versions of record or the final published versions. They should not be cited or distributed as the published version of this manuscript.

BMJ Open is an open access journal and the full, final, typeset and author-corrected version of record of the manuscript is available on our site with no access controls, subscription charges or pay-per-view fees (<http://bmjopen.bmj.com>).

If you have any questions on BMJ Open's open peer review process please email info.bmjopen@bmj.com

BMJ Open

Perspectives on life participation by young adults with chronic kidney disease: an interview study

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2020-037840
Article Type:	Original research
Date Submitted by the Author:	18-Feb-2020
Complete List of Authors:	<p>Kerklaan, Jasmijn; The University of Sydney School of Public Health, Centre for Kidney Research; Children's Hospital at Westmead Centre for Kidney Research, Centre for Kidney Research</p> <p>Hannan, Elyssa; The University of Sydney School of Public Health, Centre for Kidney Research; Children's Hospital at Westmead Centre for Kidney Research, Centre for Kidney Research</p> <p>Hanson, Camilla; The University of Sydney School of Public Health, Centre for Kidney Research; Children's Hospital at Westmead Centre for Kidney Research, Centre for Kidney Research</p> <p>Guha, Chandana; The University of Sydney School of Public Health, Centre for Kidney Research; Children's Hospital at Westmead Centre for Kidney Research, Centre for Kidney Research</p> <p>Cho, Yeoungjee; Princess Alexandra Hospital, Nephrology; University of Queensland, Australasian Kidney Trials Network</p> <p>Christian, Martin; Nottingham Childrens Hospital, Paediatric Nephrology</p> <p>Hamiwka, Lorraine; Alberta Children's Hospital, Pediatric Nephrology</p> <p>Ryan, Jessica; Monash Medical Centre Clayton, Nephrology</p> <p>Sinha, Aditi; All India Institute of Medical Sciences, Pediatric Nephrology</p> <p>Wong, Germaine; The University of Sydney School of Public Health, Centre for Kidney Research; Children's Hospital at Westmead Centre for Kidney Research, Centre for Kidney Research</p> <p>Craig, Jonathan; Flinders University Faculty of Medicine Nursing and Health Sciences, College of Medicine and Public Health,</p> <p>Groothoff, Jaap; Emma Childrens Hospital AMC, Paediatric Nephrology</p> <p>Tong, Allison; The University of Sydney School of Public Health, Centre for Kidney Research; Children's Hospital at Westmead Centre for Kidney Research, Centre for Kidney Research</p>
Keywords:	Chronic renal failure < NEPHROLOGY, Dialysis < NEPHROLOGY, Renal transplantation < NEPHROLOGY, Paediatric nephrology < NEPHROLOGY

SCHOLARONE™
Manuscripts



I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our [licence](#).

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which [Creative Commons](#) licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22

Perspectives on life participation by young adults with chronic kidney disease: an interview study

Jasmijn Kerklaan, MD^{1,2}, Elyssa Hannan, BPsych (Hons)^{1,2}, Camilla S Hanson, PhD^{1,2}, Chandana Guha, M.A.^{1,2}, Yeoungjee Cho, PhD^{3,4}, Martin Christian, MD⁵, Lorraine Hamiwka, MD⁶, Jessica Ryan, PhD⁷, Aditi Sinha, MD⁸, Germaine Wong, PhD^{1,2}, Jonathan C Craig, PhD⁹, Jaap Groothoff, PhD¹⁰, Allison Tong, PhD^{1,2}

Author affiliations

23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52

¹Sydney School of Public Health, The University of Sydney, Sydney, NSW, Australia

²Centre for Kidney Research, The Children's Hospital at Westmead, Westmead, NSW, Australia

³Department of Nephrology, Princess Alexandra Hospital, Brisbane, Australia

⁴Australasian Kidney Trials Network at the University of Queensland

⁵Department of Paediatric Nephrology, Nottingham Children's Hospital, Nottingham, UK

⁶Division of Pediatric Nephrology, Alberta Children's Hospital, University of Calgary, Calgary, Alberta
Canada

⁷Department of Nephrology, Monash Medical Centre, Melbourne, Australia

⁸Division of Nephrology, Department of Pediatrics, All India Institute of Medical Sciences, India

⁹College of Medicine and Public Health, Flinders University, Adelaide, South Australia, Australia

¹⁰Department of Pediatric Nephrology, Emma Children's Hospital, Academic Medical Center, Amsterdam,
The Netherlands

Corresponding author:

Jasmijn Kerklaan

Centre for Kidney Research, The Children's Hospital at Westmead, Westmead, NSW 2145, Sydney,

1 Australia

2 Phone: + 31 6 53142075

3 Email: kerklaan.j@gmail.com

4
5
6
7 **Wordcount (body):** 4183

8
9
10
11 **Keywords:** chronic kidney disease, young adults, life participation, dialysis, transplant

12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

For peer review only

Abstract

Objective: To describe the perspectives on life participation by young adults with childhood-onset chronic kidney disease (CKD).

Design: Semi-structured interviews; thematic analysis

Setting: Multiple centres across six countries (Australia, Canada, India, United Kingdom, United States and New-Zealand)

Participants: Thirty young adults aged 18-35 years diagnosed with CKD during childhood

Results: We identified six themes: struggling with daily restrictions (debilitating symptoms and side effects, giving up valued activities, impossible to attend school and work, trapped in a medicalized life, overprotected by adults, and cautious to avoid health risks); lagging and falling behind (delayed independence, failing to keep up with peers, and socially inept); defeated and hopeless (incapacitated by worry, an uncertain and bleak future, unworthy of relationships, and low self-esteem and shame); reorienting plans and goals (focusing on the day to day, planning parenthood, and forward and flexible planning); immersing oneself in normal activities (refusing to miss out, finding enjoyment, determined to do what peers do, and being present at social events); and striving to reach potential and seizing opportunities (encouragement from others, motivated by the illness, establishing new career goals, and grateful for opportunities).

Conclusions: Young adults encounter lifestyle limitations and missed school and social opportunities as a consequence of developing CKD during childhood and as a consequence lack confidence and social skills, are uncertain of the future, and feel vulnerable. Some re-adjust their goals and become more determined to participate in “normal” activities to avoid missing out. Strategies are needed to improve life participation in young adult ‘graduates’ of childhood CKD and thereby strengthen their mental and social wellbeing and enhance their overall health.

Strengths and limitations of this study

- Semi-structured interviews were conducted with young adults aged 18-35 years diagnosed with CKD during childhood, who were purposively sampled across six countries to obtain in-depth and diverse data on their perspectives on life participation.
- We conducted interviews until data saturation.
- Participants were all interviewed in English language and most participants were from high-income countries, therefore the transferability of the findings to other populations and settings is uncertain.
- Few participants were receiving dialysis at the time of the study though most of the participants had been on dialysis previously and discussed their past experiences.

Funding statement

Dr Tong is supported by a National Health and Medical Research Council Program Grant (ID 1092957).

The funding organizations had no role in the design and conduct of the study; collection, management, analysis and interpretation of the data; preparation, review, or approval of the manuscript.

Competing interests statement

The authors do not have any competing interests or conflicts of interest to declare.

INTRODUCTION

Chronic kidney disease (CKD) in children is associated with increased mortality and may lead to impaired physical, social, and cognitive functioning¹⁻⁶. These challenges undermine the ability of children with CKD to achieve developmental milestones, autonomy, and independence, which can in turn limit successful participation in society during adulthood⁷⁻⁹. Young adults with childhood-onset of CKD have reported difficulties and delays in attaining educational, vocational and relationship goals, and are less likely to be employed than the age-matched general population^{10,11}.

Through a global consensus process that involved over 700 patients, caregivers and health professionals from more than 70 countries, the Standardised Outcomes in Nephrology – Children and Adolescents (SONG-Kids) initiative established life participation as the most important patient-reported outcome for children with CKD¹²⁻¹⁴. The World Health Organization defines life participation as “involvement in a life situation”¹⁵ and recognizes this as a critical concept in defining functioning, disability and health. For children with CKD, meaningful life activities include study, sport, social and leisure activities. Life participation is often restricted by the symptoms, side-effects, and treatment burden associated with CKD, and this has long-term consequences in young adulthood^{7,8,16,17}.

There is increasing recognition of the need to address the ability to participate in life^{10,17}, as this may also impact on motivation for self-management, coping, and treatment satisfaction. However, little is known about patients’ perspectives on the meaning and impact of childhood CKD on ‘life participation’. The aim of this study was to describe the perspectives of young adults with childhood-onset CKD on life participation, to inform interventions and clinical care and ultimately to improve health outcomes for patients with CKD.

METHODS

We followed the Consolidated Criteria for Reporting Qualitative Health Research (COREQ) to report this study¹⁸ (Supplementary File 1).

Participant Selection and Setting

Participants were eligible to participate if they were English-speaking, aged from 18 to 35 years old, and diagnosed with CKD prior to the age of 18 years. We included any cause of kidney disease and treatment stage of CKD (CKD Stage 1-5 (not receiving kidney replacement therapy), dialysis, or transplant). Those determined to be medically unsuitable by their clinician were excluded. Participants were recruited through the SONG network using standardized invitation emails and by clinicians from centres across Australia, Canada, India, United Kingdom and United States. Ethics approval was obtained from all participating sites listed in Supplementary File 2. We applied a purposive sampling strategy to ensure a diverse range of demographic and clinical characteristics.

Data collection

The interview guide was developed based on the literature on life participation and discussion among the research team^{14,15} (Supplementary File 3). The questions focused on the meaning and impact of childhood CKD on life participation during childhood and in young adulthood. From September to November 2019 author JK conducted one semi-structured interview with each participant face-to-face at a venue as preferred by the participant, or by video conference using zoom. We conducted interviews until we reached data saturation, that is, when no new concepts on life participation were raised after three consecutive interviews. All the interviews were digitally audio-recorded and transcribed.

Data Analysis

The transcripts were imported into HyperRESEARCH (version 4.0.3) software. Using thematic analysis, JK coded line-by-line all meaningful segments of text in the transcripts to inductively identify concepts, which

1 were grouped into initial themes and subthemes. We identified patterns and links among themes to develop a
2 thematic schema. To ensure the themes captured the breadth and depth of the data, these were discussed
3 with EH, CH and AT, who also read the transcripts, and participants were emailed a copy of the preliminary
4 findings and invited to provide comments. Any additional perspectives received were integrated into the
5 final analysis.
6
7
8
9
10
11
12
13

14 **Patient and Public Involvement**

15 Patients were directly involved in the study as participants in the interviews. Author CG is a caregiver who
16 was involved in the design of the study.
17
18
19
20
21
22
23
24

25 **RESULTS**

26 **Study Participants**

27 Overall, 30 young adults from Australia (n=16), Canada (n=5), India (n=4), United Kingdom (n=3), United
28 States (n=1) and New-Zealand (n=1) were included. They were between 18 to 32 years of age (mean 23.4
29 years, SD 4.0), and 20 (67%) were female. Non-participation was due to refusal, illness, or inability to
30 schedule an interview after three attempts. The participant characteristics are shown in Table 1. The average
31 age at diagnosis was 7.7 years (SD 5.3). Seven (23%) participants were not receiving kidney replacement
32 therapy, two (7%) were receiving dialysis, and 21 (70%) had a kidney transplant. The average duration of
33 the interview was 53 minutes, with 14 interviews (47%) were conducted face to face. A parent was present
34 in five interviews (17%).
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52

53 **Themes**

54 We identified six major themes: struggling with daily restrictions, lagging and falling behind, defeated and
55 hopeless, reorienting plans and goals, immersing oneself in normal activities, and striving to reach potential
56 and seizing opportunities. Each theme is expounded by subthemes, which are described in the following
57
58
59
60

1 section. Figure 1 depicts how the themes relate to each other. Selected quotations to support each theme are
2 provided in Table 2.
3
4
5
6

7 **Struggling with daily restrictions**

8
9 *Debilitating symptoms and side effects:* Symptoms and side effects such as infections, tiredness, and pain
10 limited the participants' day-to-day activities. Fatigue made them "too tired to do anything", and "unable to
11 get up in the morning". For some, swelling impaired their mobility – "I couldn't move because of my
12 swollen ankles". Specific side-effects of immunosuppression, including weight gain, osteoporosis, hair
13 growth, and cognitive impairment restricted daily activities and prevented them from excelling (e.g. sports)
14 and caused some to drop out of college/university.
15
16
17
18
19
20
21
22
23
24

25 *Giving up valued activities:* Some felt forced to stop doing things they enjoyed, particularly sports including
26 swimming, football and rugby – "the [doctors] told me to quit the team". They resented having to forgo
27 activities they valued – "I hated that I wasn't well enough to go to my dance school and I pretty much gave
28 up dancing." Some had to refrain from foods they liked because of the dietary restrictions, or were
29 disappointed about being unable to travel – "I'd rather backpack, I'd rather go to a random country, but I
30 can't."
31
32
33
34
35
36
37
38
39
40
41

42 *Impossible to attend school and work:* Attending school was "a big juggling act", and some missed years of
43 education. Being too tired, unwell, and having to do dialysis or undergo surgery had prevented them from
44 attending school. Some felt self-conscious and wanted to stay home – "I was physically uncomfortable,
45 because of tubes sticking out of my stomach and chest. I just wanted to be home all the time". One
46 participant was home schooled for over a year because of the risk of infection. Some had to take time off
47 work because of treatment.
48
49
50
51
52
53
54
55
56
57

58 *Trapped in a medicalized life:* The frequent and lengthy hospital appointments, dialysis regimen, surgeries
59 and having to take medications consumed their childhood. They were not allowed to go to school camp or
60

1 sleepovers because they had tubes and lines and needed to remain close to the hospital in case they needed
2 medical attention – “I am always going to have to be tied to the hospital because that's my lifeline, for
3 medications, blood tests, doctor appointments, checkups. It's always going to be at the forefront of my life.”
4
5 For patients receiving dialysis, they were “stuck to the machine.” Some could not spend the night with their
6
7 partner because they had to be home to do peritoneal dialysis. One participant mentioned that having
8
9 multiple surgeries (“20 surgeries in 21 months”) precluded them from educational and social activities.
10
11 Some participants felt “left to their own devices” after kidney transplant because they had been
12
13 “institutionalized” while on dialysis.
14
15
16
17
18
19
20

21 *Overprotected by adults:* Some believed that overprotectiveness by adults inhibited their ability to live life
22
23 freely and with confidence – “Because they [my parents] were protective of me, I became a bit fearful, I
24
25 became scared of a lot of things.” Some were made to wear a medical mask or remain inside their house for
26
27 no apparent medical reason. Some also felt that doctors and teachers kept them “in a bubble” by advising
28
29 them against playing sports or travelling – “I've talked to Dr. X about it, but because his other patients have
30
31 gotten really sick, he's telling me not to go [travel to Asia].”
32
33
34
35
36

37 *Cautious to avoid health risks:* Some were cautious and vigilant to avoid health risks to avoid being blamed
38
39 for getting sick. They always considered the consequences of their behavior and questioned, “is this going to
40
41 affect my kidney?” They were not able to drink alcohol or travel to certain places. They were constantly
42
43 planning ahead for simple tasks such as what they would eat and drink. Participants from India mentioned
44
45 being particularly careful not to get an infection when leaving the house.
46
47
48
49
50

51 **Lagging and falling behind**

52
53 *Delayed independence:* Participants felt they lacked the foundations for developing into independent adults
54
55 and were unprepared for the future. Those who were on dialysis during childhood felt their lives had been
56
57 put on hold – “ I have missed three years of my life”. Some had to live with their parents because they
58
59 depended on them for financial support and were concerned about their ability to sustain employment and
60

1 afford housing during periods of ill health – “I’d like to move out, but if anything serious happens and I
2 can’t work, I can’t pay for the place anymore.” They felt their ability to gain independence was limited
3 because they had “grown up with pretty much everything being done for me”.
4
5
6
7
8

9 *Failing to keep up with peers:* Some were too tired and unable to concentrate and were often “falling asleep
10 in school”. They missed learning the basics and felt unable to reach their potential – “Now I experience
11 difficulty while studying... if my basics were better, I would have scored higher [in mathematics].” Some
12 were upset as they watched their classmates graduate while they were left behind – “I was studying
13 engineering and I watched a lot of my friends go on and graduate from that program.” This led them to feel
14 lacking in intelligence and skills compared with their peers.
15
16
17
18
19
20
21
22
23

24
25 *Socially inept:* Having missed out on interacting with friends because of childhood CKD, some felt they
26 lacked social skills as a young adult and felt “awkward” and suffered “social anxiety” – “I’ve missed out on
27 like the social side to life as a kid ... I have social anxiety. I struggle with big crowds and the work
28 Christmas party I don't go to.” Some felt alone and isolated. One participant was confined at home during
29 childhood to avoid infection – “No one could really come over. I was just in my room for a little bit over a
30 year.” Some withdrew from others because they “didn’t feel like being around people” to avoid stigma, pity
31 and having to explain themselves. Some lost friends or felt forgotten by them or became distanced from
32 former friends because CKD had changed who they were and what they could do.
33
34
35
36
37
38
39
40
41
42
43
44
45

46 **Defeated and hopeless**

47
48 *Incapacitated by worry:* Participants worried about their health and “dying young” – “I feel like I’m
49 definitely going to die younger than a lot of my family”. Some participants, not yet on kidney replacement
50 therapy worried about “having to rely on a [dialysis] machine in the future”. Transplant recipients were
51 concerned about graft failure. Some were “living their lives on hold” because of the constant daily worries –
52 “I get in a bad headspace and worrying about things that haven’t even happened yet [transplant failure]”.
53
54
55
56
57
58
59
60

1 *An uncertain and bleak future:* At times, when “they didn’t see the point anymore,” they wanted to give up –
2
3 “When the doctor said, ‘Oh you might need to be on dialysis.’ It kind of just made me give up in school”.
4
5 Some participants, particularly those with genetic kidney disease, braced themselves for deteriorating health
6
7 and consequent restrictions – “My life participation is going to decline and that I won’t be able to do things”.
8
9 Participants who did not know the cause of their kidney disease felt “insecure” about the future.
10
11
12
13

14 *Unworthy of relationships:* Some worried about “ending up alone,” because they felt they “weren’t good
15
16 enough” for a partner and thought “no one would ever love them”. One participant from India explained: “if
17
18 you have to buy an apple, you will take a fresh one, not the one that has a hole in the middle. They will
19
20 choose the healthy one [for an arranged marriage]”. Another recalled their partner breaking up with them
21
22 because of kidney disease – “he said, ‘I want an active future. I don’t want a future where I’m in and out of
23
24 hospital with someone””.
25
26
27
28
29

30 *Low self-esteem and shame:* Childhood CKD impaired self-esteem through to adulthood – “I am still not
31
32 fully confident about myself, and this would not have happened [if I didn’t have CKD as a child].” Some
33
34 became “upset looking in the mirror”, felt “ashamed” or “avoided going out” because of CKD and
35
36 treatment-related weight gain, stretch marks or scars – “I didn’t want to do anything because I had fluids
37
38 [swelling] everywhere and I just wanted to be normal”. Some reported being bullied by others because of
39
40 CKD.
41
42
43
44
45

46 **Reorienting plans and goals**

47
48 *Focusing on the day to day:* Thinking about the future was difficult because of the unpredictability of the
49
50 kidney disease, so instead participants focused on “living in the present” and “doing a day at a time”. Some
51
52 explained that whenever they planned their future, “it never seemed to happen” [going back to school or
53
54 work]. Patients who had been on dialysis formed a habit of concentrating on getting through each day.
55
56
57
58
59

60 *Planning parenthood:* Some felt pressured to think about parenthood at a young age, when they were not

1 ready to have a family, and said doctors advised to “have children as soon as possible”, “get their eggs
2 harvested” or advised that “it was going to be more difficult due to previous treatments and medication.”
3
4 One participant said, “to become a father I will have to do IVF”. Some feared the possibility of genetic
5
6 transmission and causing their child to suffer – “I will never have my own kids, because I don’t know how I
7
8 got the disease. Because if he or she ends up having a problem, I will be blaming myself”. Some women
9
10 were concerned about jeopardizing their kidney health (or graft) by becoming pregnant.
11
12
13
14
15

16 *Forward and flexible planning:* Participants had to think ahead, change goals or make adjustments to their
17
18 lives because of kidney disease, which was frustrating though some learned to accept this. Some transplant
19
20 recipients tried to find part-time work in case they lost their graft. Participants with fluid and diet restrictions
21
22 would “save” their intake so they could eat and drink more freely at social events – “I will not eat potassium
23
24 foods and I’ll be careful today with water, so when I get to the party, I can actually have a soft drink”. Some
25
26 established daily and travel schedules around the medication regimen.
27
28
29
30
31

32 **Immersing oneself in normal activities**

33
34 *Refusing to miss out:* Some strived to do “normal” things refusing to let the CKD stop them. They “didn’t
35
36 see themselves as unable to do things”. Some made adjustments to enable them to play sports – “We did
37
38 five-a-side football, which I was able to do because they made like a special shield that went over the
39
40 kidney”. They were adamant not to fixate on restrictions.
41
42
43
44
45

46 *Finding enjoyment:* Some learned to enjoy life more and to “appreciate the little things” because of the
47
48 kidney disease, making every effort to “enjoy every day and have fun”. During dialysis, patients developed
49
50 new hobbies or invited friends to visit and play card games.
51
52
53
54

55 *Determined to do what peers can do:* Some were determined to do what their peers could do. During
56
57 childhood, they desired “to be normal” and to “be able to do everything everyone else did,” which also
58
59 included drinking – “I still went out and drank, because I wanted to be normal”.
60

1
2
3 *Being present at social events:* Being able to socialize and “hang out” with friends and family was important
4
5 – “[kidney disease] doesn’t impact me that it stops me from going out and having a social life”. At times,
6
7 they had, “friends joining my dialysis session” or “parents joining a school camp”.
8
9

11 **Striving to reach potential and seizing opportunities**

12
13
14 *Encouragement from others:* Participants talked about how “not being treated differently or as if they
15
16 couldn’t do things” helped them stay motivated and not to feel like a patient. Some found it helpful to meet
17
18 others with kidney disease, “people that understood” – “that was the point where my whole attitude towards
19
20 everything changed, because I realized that I wasn’t alone and I realized that actually people were coping
21
22 with it”.
23
24

25
26
27
28 *Motivated by the illness:* For some, CKD gave them “a reason to do things” and motivated them “to make
29
30 healthier choices in life”. Some made it their mission to be as fit as possible to “slow down” the disease.
31
32 Some were inspired to support and mentor other children and young adults with kidney disease – “I’m there
33
34 for the new generation, to help them cope and be that inspiration”.
35
36

37
38
39 *Establishing new career goals:* Some changed career path because they felt they lacked education, had
40
41 health problems or wanted to avoid the risk of infection – “I’d probably go into something with childcare.
42
43 But because of infection and stuff, that’s probably not a good idea”. Others redirected their goals to pursue
44
45 work in healthcare because the disease made them realize they wanted to be a “doctor, “nurse” or “social
46
47 worker” – “it made me realize that I wanted to be a nurse. I suppose that’s a good thing out of a bad
48
49 situation”.
50
51

52
53
54
55 *Grateful for opportunities:* Some participated in activities (e.g. world transplant games, cruises) that were
56
57 organized by the hospitals, support groups and charity organizations. – “I probably never would have
58
59 experienced that [if I didn’t have kidney disease]”. Having experienced illness in childhood made them
60

1 grateful for what they were able to do now as young adults – “when I go on a hike or to the gym, I’m like, I
2 am so lucky. I’m so grateful that I can do these things because I wasn’t able to do it before”.

9 DISCUSSION

14 Young adults with childhood-onset CKD struggled with day-to-day restrictions and limitations in their
15 ability to work, study and participate in social and leisure activities because of symptoms and side effects
16 and burden of treatment, the need to minimize health risks, and being overprotected by adults. They felt
17 unable to keep up with their peers and attributed social anxiety and feelings of inferiority to missing out on
18 social interaction and school during childhood. Some were frustrated in having to remain dependent on their
19 parents and being unable to gain independence, move out of home, and establish relationships, feeling
20 defeated and hopeless about their future. These challenges meant they had to reorient their plans and goals.
21 Some became determined to immerse themselves in normal activities and to take every opportunity to do
22 what their peers were able to do. They reflected that childhood CKD gave them opportunities they would not
23 have had otherwise (e.g. participating in transplant games), or motivated them to establish career goals, for
24 example in counseling and nursing.

41 These findings were broadly consistent across the different demographic and clinical characteristics of
42 participants, and their care settings. However, we noted some differences by age group, age at diagnosis,
43 country and experience of dialysis. Younger participants reported difficulties with attending school/study
44 and keeping up with peers, dropping out of higher education, and were concerned about missing social
45 events. Older participants were focused on being able to work and establish a career path given their
46 uncertain prognosis, and seemed to contemplate longer term consequences. Those who were diagnosed with
47 kidney disease at an older age found it more difficult to give up valued activities such as sport. There were
48 some specific concerns such as infection, identified by participants in India, which may be attributable to the
49 higher risk¹⁹. They also worried about being “unsuitable” for arranged marriage. Participants who had been

1 on dialysis for a longer period of time during childhood seemed to face, to a greater extent, loss of friendship
2 and inability to participate in recreational activities.
3
4
5

6
7 Our findings reflect those of previous studies²⁰, which have also found that young adults with childhood-
8 onset CKD report difficulties with education, employment and social relationships²¹⁻²⁴, and perceive that
9 their lives are “on hold”^{25,26}. These problems of life participation have also been documented in studies in
10
11 young people diagnosed with other childhood chronic conditions, including cystic fibrosis, hematological
12 and autoimmune disease, who also feel impaired in their social interactions and capacity to keep up with
13
14 peers²⁷ and have lower life satisfaction²⁸. Our study further reveals that young adults believe that missing
15
16 school and social opportunities, and being “overprotected” during childhood caused them to lack the
17
18 fundamental skills and confidence for social interaction, and develop independence to participate in life as
19
20 autonomous adults. Consequently, this instilled vulnerability, uncertainty and fear of their future in terms of
21
22 day-to-day functioning, and setting and pursuing educational and career goals.
23
24
25
26
27
28
29
30
31

32 This study was multinational and offers in-depth insights gained from a reasonably diverse group of young
33
34 adults with childhood-onset CKD. We achieved data saturation and used investigator triangulation to ensure
35
36 that the themes reflected the breadth and depth of the data. However, there are some potential limitations.
37
38 Most participants were from high-income countries, therefore the transferability of the findings to other
39
40 populations and settings is uncertain. The sample was skewed in relation to gender with only one third of the
41
42 population being male, while CKD affects more male. This could be a weakness we want to acknowledge.
43
44 Only two patients were receiving dialysis at the time of the study though most of the participants had been
45
46 on dialysis previously and discussed their past experiences. Some interviews were conducted with parents
47
48 present, but we are unable to determine if this inhibited open responses.
49
50
51
52
53
54

55 There is a need to improve life participation in patients with childhood CKD and strategies that encompass
56
57 psychosocial, educational and vocational support delivered in both the pediatric and adult healthcare settings
58
59 are suggested. A multidisciplinary model of care involving nephrologists, psychologists, social workers and
60

1 occupational therapists may help to bring awareness and address the barriers to life participation. For
2 example by managing unresolved anxiety, uncertainty and fears to strengthen confidence and self-esteem in
3 participating in activities, establishing relationships, and decision-making about parenthood. Identifying and
4 building social networks may motivate and support young patients to develop independence, autonomy, and
5 determination to engage in life activities and work towards their goals. Online support groups and camps
6 could promote a sense of normality and social inclusion²⁹. School-based interventions, that includes
7 advocacy for patients to increase understanding among their peers and individual tutoring may improve
8 social and educational outcomes³⁰. Social workers and potentially peer navigators, could assist young adults
9 with finding employment, and accessing social benefits and housing²³. Given the medical, ethical, and
10 emotional complexities of fertility and parenthood in CKD, we suggest counselling that is sensitive to
11 patients' preparedness and life priorities^{31,32}.

12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28 Rehabilitation programs may have potential in young people with chronic kidney disease. Trials of
29 cognitive-based problem-solving strategies improved level of activity and life participation in children with
30 other conditions including development coordination disorder and cerebral palsy^{33,34}. This study used a
31 strategy comprised of identifying occupational performance problems by the children and their parents, and
32 conducting weekly group sessions for 10 weeks, along with 15 minutes per day of home activities. Physical
33 rehabilitation programs for adults on dialysis have been shown to improve the ability to perform daily
34 activities and physical functioning³⁵. This particular program comprised of an assessment of level of activity
35 and functional ability, collaborative goal setting that accounted for patient's preferences and lifestyle,
36 problem solving to address barriers to physical activity, and identifying social supports to maintain an
37 increased level of activity. Similar rehabilitation program may be adapted for young people with chronic
38 kidney disease, focused on relevant activities in this population.

39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55 Whilst the need to improve life participation in young adults with childhood CKD is evident, trials of
56 interventions to improve the aspects of life participation prioritized by our participants are sparse.

57
58
59
60 Recognizing that patient involvement in research improves the relevance, implementation and uptake of

1 research³⁶, we suggest that future studies should involve patients in co-designing and evaluating
2 interventions. Also, we recognize that assessing this outcome may be challenging as there is currently no
3 patient-reported outcome measure for life participation validated for use in this population. Further work is
4 needed to identify or establish a patient-reported outcome that includes the dimensions of life participation
5 that are important to children and young adults with CKD.
6
7
8
9
10
11
12
13

14 Young adults encounter lifestyle limitations and missed school and social opportunities during childhood
15 CKD and as a consequence feel lacking in confidence and social skills, uncertain of the future, and
16 vulnerable. Some re-adjust their goals and become more determined to participate in “normal” activities to
17 avoid missing out. Strategies and interventions are needed to improve life participation in young adults with
18 childhood CKD and thereby strengthen their mental and social wellbeing and enhance overall health.
19
20
21
22
23
24
25
26
27
28

29 **Acknowledgements**

30 We thank all participants for sharing their interesting and thoughtful perspectives in this study.
31
32
33
34
35
36

37 **Author contributions**

38 Research idea and study design: AT, JK; data acquisition: JK; data analysis/interpretation: JK, EH, CH, AT;
39 supervision or mentorship: AT, JG, JCC. AT, JG, JCC, YC, MC, LH, JR, AS and GW contributed important
40 intellectual content during manuscript drafting or revision and accepts accountability for the overall work by
41 ensuring that questions pertaining to the accuracy or integrity of any portion of the work are appropriately
42 investigated and resolved.
43
44
45
46
47
48
49
50
51
52
53

54 **Ethics approval**

55 All participants provided written informed and voluntary consent. The study was approved by The
56 University of Sydney, The Sydney Children’s Hospital Network (Westmead, Sydney, NSW, Australia),
57
58
59
60

1 Royal Children's Hospital (Monash Health, Melbourne, VIC, Australia) and Princess Alexandra Hospital
2
3 (Brisbane, QLD, Australia).
4
5
6
7

8 **Data sharing**

9

10 No additional data are available.
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

For peer review only

References

1. Gerson AC, Wentz A, Abraham AG, *et al.* Health-related quality of life of children with mild to moderate chronic kidney disease. *Pediatrics* 2010;**125**:e349-e57.
2. Tong A, Tjaden L, Howard K, *et al.* Quality of life of adolescent kidney transplant recipients. *J Pediatr* 2011;**159**:670-5.
3. Lande MB, Gerson AC, Hooper SR, *et al.* Casual blood pressure and neurocognitive function in children with chronic kidney disease: a report of the children with chronic kidney disease cohort study. *Clin J Am Soc Nephrol* 2011;**6**:1831-7.
4. Haavisto A, Korkman M, Holmberg C, *et al.* Neuropsychological profile of children with kidney transplants. *Nephrol Dial Transplant* 2011;**27**:2594-601.
5. Hooper SR, Gerson AC, Johnson RJ, *et al.* Neurocognitive, social-behavioral, and adaptive functioning in preschool children with mild to moderate kidney disease. *J Dev Behav Pediatr* 2016;**37**:231.
6. Thys K, Schwering KL, Siebelink M, *et al.* Psychosocial impact of pediatric living-donor kidney and liver transplantation on recipients, donors, and the family: a systematic review. *Transpl Int* 2015;**28**:270-80.
7. Groothoff J, Grootenhuis M, Dommerholt A, *et al.* Impaired cognition and schooling in adults with end stage renal disease since childhood. *Arch Dis Child* 2002;**87**:380-5.
8. Groothoff JW, Grootenhuis MA, Offringa M, *et al.* Social consequences in adult life of end-stage renal disease in childhood. *J Pediatr* 2005;**146**:512-7.
9. Rocha S, Fonseca I, Silva N, *et al.* Impact of pediatric kidney transplantation on long-term professional and social outcomes. *Transplant Proc* 2011;**43**:120-4.
10. Tjaden LA, Grootenhuis MA, Noordzij M, *et al.* Health-related quality of life in patients with pediatric onset of end-stage renal disease: state of the art and recommendations for clinical practice. *Pediatr Nephrol* 2016;**31**:1579-91.
11. Mellerio H, Alberti C, Labèguerie M, *et al.* Adult social and professional outcomes of pediatric renal transplant recipients. *Transplantation* 2014;**97**:196-205.
12. Hanson CS, Gutman T, Craig JC, *et al.* Identifying Important Outcomes for Young People With CKD and Their Caregivers: A Nominal Group Technique Study. *Am J Kidney Dis* 2019;**74**:82-94.

13. Tong A, Samuel S, Zappitelli M, *et al.* Standardised Outcomes in Nephrology—Children and Adolescents (SONG-Kids): a protocol for establishing a core outcome set for children with chronic kidney disease. *Trials* 2016;**17**:401.
14. Standardised Outcomes in Nephrology – Children and Adolescents (SONG-Kids), 2019. Available: <https://songinitiative.org/projects/song-kids/> [Accessed 1st December 2019].
15. World Health Organization. International classification of functioning, disability and health: ICF: Geneva: World Health Organization; 2001.
16. Groothoff J. Long-term outcomes of children with end-stage renal disease. *Pediatr Nephrol* 2005;**20**:849-53.
17. Tjaden LA, Vogelzang J, Jager KJ, *et al.* Long-term quality of life and social outcome of childhood end-stage renal disease. *J Pediatr* 2014;**165**:336-42.
18. Booth A, Hannes K, Harden A, *et al.* COREQ (consolidated criteria for reporting qualitative studies). Guidelines for reporting health research: A user's manual 2014:214-26.
19. World Health Organization. Global Health Estimates, 2016. Available: https://www.who.int/healthinfo/global_burden_disease/estimates/en/index1.html [Accessed 1st December 2019].
20. Hamilton AJ, Caskey FJ, Casula A, *et al.* Psychosocial Health and Lifestyle Behaviors in Young Adults Receiving Renal Replacement Therapy Compared to the General Population: Findings From the SPEAK Study. *Am J Kidney Dis* 2019;**73**:194-205.
21. Tong A, Henning P, Wong G, *et al.* Experiences and perspectives of adolescents and young adults with advanced CKD. *Am J Kidney Dis* 2013;**61**:375-84.
22. Cura J. Interpreting transition from adolescence to adulthood in patients on dialysis who have end-stage renal disease. *Journal of renal care* 2012;**38**:118-23.
23. Murray PD, Dobbels F, Lonsdale DC, *et al.* Impact of end-stage kidney disease on academic achievement and employment in young adults: a mixed methods study. *Journal of Adolescent Health* 2014;**55**:505-12.

- 1 24. Lewis H, Arber S. Impact of age at onset for children with renal failure on education and
2 employment transitions. *Health*: 2015;**19**:67-85.
- 3
4 25. Crowley-Matoka M. Desperately seeking “normal”: the promise and perils of living with kidney
5 transplantation. *Soc Sci Med* 2005;**61**:821-31.
- 6
7 26. Molzahn AE, Bruce A, Shields L. Learning from stories of people with chronic kidney disease.
8
9
10
11
12
13
14
15 27. Nap-van der Vlist MM, Kars MC, van der Sprenkel EEB, *et al*. Daily life participation in childhood
16 chronic disease: a qualitative study. *Arch Dis Child* 2019.
- 17
18 28. Matthie N, Hamilton J, Wells D, *et al*. Perceptions of young adults with sickle cell disease
19 concerning their disease experience. *J Adv Nurs* 2016;**72**:1441-51.
- 20
21
22
23 29. Allen C, Vassilev I, Kennedy A, *et al*. Long-term condition self-management support in online
24 communities: a meta-synthesis of qualitative papers. *J Med Internet Res* 2016;**18**:61.
- 25
26
27 30. Lansing L. Back to school for the child on long-term hemodialysis. *AANNT J* 1981;**8**:13.
- 28
29 31. Bramham K, Lightstone L. Pre-pregnancy counseling for women with chronic kidney disease. *J*
30
31
32
33
34
35
36
37
38 32. Wiles KS, Bramham K, Vais A, *et al*. Pre-pregnancy counselling for women with chronic kidney
39 disease: a retrospective analysis of nine years’ experience. *BMC nephrol* 2015;**16**:28.
- 40
41
42
43 33. Cameron D, Craig T, Edwards B, *et al*. Cognitive Orientation to daily Occupational Performance
44 (CO-OP): A new approach for children with cerebral palsy. *Phys Occup Ther Pediatr* 2017;**37**:183-98.
- 45
46
47
48
49 34. Thornton A, Licari M, Reid S, *et al*. Cognitive orientation to (daily) occupational performance
50 intervention leads to improvements in impairments, activity and participation in children with
51 Developmental Coordination Disorder. *Disabil Rehabil* 2016;**38**:979-86.
- 52
53
54 35. Tawney KW, Tawney PJ, Hladik G, *et al*. The life readiness program: a physical rehabilitation
55 program for patients on hemodialysis. *Am J Kidney Dis* 2000;**36**:581-91.
- 56
57
58 36. Liabo K, Boddy K, Burchmore H, *et al*. Clarifying the roles of patients in research. *BMJ*
59
60 2018;**361**:k1463.

Figure Legends

Figure 1. Thematic schema

For peer review only

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46

Table 1. Participant characteristics

Characteristics	N	(%)
Sex		
Men	10	(33)
Women	20	(67)
Age group (years)		
18-21	12	(40)
22-25	9	(30)
26-30	7	(23)
31-35	2	(7)
Country		
Australia	16	(55)
Canada	5	(17)
India	4	(13)
United Kingdom	3	(10)
United States	1	(3)
New-Zealand	1	(3)
Highest level of education		
Primary School	1	(3)
Secondary school, grade 10	4	(13)
Secondary school, grade 12	6	(20)
Tertiary, certificate/diploma	4	(13)
Tertiary, undergraduate/bachelor	13	(43)
Tertiary, Postgraduate/ Masters/PhD	2	(7)
Employment status		
Full time	6	(20)
Part time or casual	7	(23)
Student	13	(43)
Voluntary work	1	(3)
Not employed	4	(13)
Marital status		
Married	4	(13)
Partner (living together)	4	(13)
Partner (not living)	4	(13)
Divorced/separated	0	(0)
Single	18	(60)
Living with		
Parents/family	19	(63)
Housemates	2	(7)
Partner	7	(23)
By themselves	2	(7)
No. of children		
0	28	(93)
1	2	(7)

Clinical characteristics	N	(%)
Age at CKD diagnoses (years)		
Prenatal or at birth	2	(7)
0-5	7	(23)
6-10	9	(30)
11-15	8	(27)
16+	4	(13)
CKD diagnosis or cause		
Congenital abnormalities of kidney/urinary tract	7	(23)
Focal segmental glomerulosclerosis	4	(13)
Nephrotic Syndrome (cause not specified)	3	(10)
Polycystic kidney disease	3	(10)
Hemolytic Uremic Syndrome	2	(7)
Lupus Nephritis	2	(7)
Reflux Nephropathy	2	(7)
Granulomatosis with polyangiitis	1	(3)
Henoch Schönlein Purpura	1	(3)
Diabetic	1	(3)
Unknown	1	(3)
Other	3	(10)
Current CKD treatment stage		
Not on kidney replacement therapy	7	(23)
5D, hemodialysis	2	(7)
5D, peritoneal dialysis	0	(0)
5T, deceased donor kidney transplant	13	(43)
5T, living donor kidney transplant	8	(27)
Treatment during childhood*		
No kidney replacement therapy	15	
Hemodialysis	8	
Peritoneal dialysis	8	
Transplant	13	

Note: N = 30. Percentage may not total 100 due to rounding.

* = May not add up, because of possible multiple answers per person

Table 2. Selected participant quotations for each theme

For peer review only

List of Supplementary Files

Supplementary File 1. COREQ criteria

Supplementary File 2. Ethics approval

Supplementary File 3. Interview guide

For peer review only

Figure 1. Thematic schema



Supplementary File 1. COREQ Checklist

No.	Item	Comment
Domain 1: Research team and reflexivity		
1	Interview/facilitator	JK
2	Credentials	JK (MD)
3	Occupation	JK, Medical Student
4	Gender	JK (Female)
5	Experience and training	Completed training in qualitative research
6	Relationship established	There were no prior relationships established.
7	Participant knowledge of the interviewer	Not known to participants prior to the study
8	Interviewer characteristics	Female, medical student
Study design		
9	Theoretical framework	Qualitative study (using techniques from grounded theory)
10	Sampling	Purposive
11	Method of approach	Email/phone
12	Sample size	N=30 See table 1
13	Non-participation	Three did not participate because of conflicting schedules.
14	Setting of data collection	A venue as preferred by the participant, or by video conference using zoom
15	Presence of non-participants	Yes, a parent was present in five interviews.
16	Description of sample	Refer to Table 1
17	Interview guide	Provided in Supplementary File 3
18	Repeat interviews	Single interview conducted
19	Audio/visual recording	Interviews were audio recorded
20	Field notes	No
21	Duration	The mean duration of the interviews was 53 minutes.
22	Data saturation	Yes
23	Transcripts returned	Yes
Analysis and findings		
24	Number of data coders	1 (JK)
25	Description of the coding tree	No – see themes
26	Derivation of themes	Inductively derived from data
27	Software	HyperRESEARCH
28	Participant checking	Yes, participants were emailed a copy of the preliminary findings and invited to provide comments and we used investigator triangulation (JK, EH, CH and AT).
29	Quotations presented	Refer to Table 2
30	Data and findings consistent	Quotations provided to illustrate each theme.
31	Clarity of major themes	Yes – themes
32	Clarity of minor themes	Yes – see subthemes and description of the themes

1
2
3 **Supplementary File 2**
4
5
6
7

8 Ethics approval and consent to participate:
9

- 10 - The University of Sydney, Sydney, NSW, Australia
11
12
13 - The Sydney Children's Hospital Network, Westmead, Sydney, NSW, Australia
14
15
16 - Royal Children's Hospital, Monash Health, Melbourne, VIC, Australia
17
18
19 - Princess Alexandra Hospital, Brisbane, QLD, Australia
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Supplementary File 3

SONG-Kids Interview guide

Introduction

1. Could you briefly tell me about your experience growing up with kidney problems/kidney disease?
2. How does CKD impact on your life at the moment? How is it different now, compared to when you were a child living with kidney disease? What are things you missed out on?

Meaning of life participation

3. Life participation, or being able participate in life, has been found to be an important thing to focus on in research in children with CKD. Caregivers, young patients and health care providers told us this was important.
 - What do you think of when I say “life participation,” what does it mean to you?
 - How would you define ‘life participation’?
4. Life participation is about being able to do the things that are meaningful and important to you. What things/activities are important to you or other young adults with kidney disease
 - Why? (work/career, income, family/having children, education, travel, intimate relationships, social life, physical activity, freedom/flexibility, independence)
5. Do you think the meaning (or the types of activities) of life participation is different between young adults with kidney disease, and young adults without kidney disease – why?

Experience of life participation during childhood

6. As a child, what areas of your life were most impacted or limited? (school, travel, social life, quality of life, physical activity, freedom and flexibility)
7. Has your ability to participate in life changed over time, throughout your journey with CKD? How?

Impact of (childhood) CKD on life participation in young adulthood

8. Has your ability to participate in life been shaped (or impacted) by having childhood CKD? How?
9. What areas of your life have been most impacted or limited? How/Why? (work/career, income, family/having children, education, travel, intimate relationships, social life, physical activity, freedom and flexibility, independence)
10. What about your future? Are there areas of your life that you believe will be impacted or limited due to CKD?

Improving life participation

11. Do you think life participation should be discussed/or addressed by health care providers – why/how?
12. Has anything helped to improve your ability to participate in life - how? What about when you were a child?
13. Can you suggest things that may be helpful to improve life participation for young adults? What about for children with kidney disease?

BMJ Open

Perspectives on life participation by young adults with chronic kidney disease: an interview study

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2020-037840.R1
Article Type:	Original research
Date Submitted by the Author:	26-Jul-2020
Complete List of Authors:	Kerklaan, Jasmijn; Emma Childrens' Hospital UMC, Paediatric Nephrology; Children's Hospital at Westmead Centre for Kidney Research, Centre for Kidney Research Hannan, Elyssa; The University of Sydney School of Public Health, Centre for Kidney Research; Children's Hospital at Westmead Centre for Kidney Research, Centre for Kidney Research Hanson, Camilla; The University of Sydney School of Public Health, Centre for Kidney Research; Children's Hospital at Westmead Centre for Kidney Research, Centre for Kidney Research Guha, Chandana; The University of Sydney School of Public Health, Centre for Kidney Research; Children's Hospital at Westmead Centre for Kidney Research, Centre for Kidney Research Cho, Yeoungjee; Princess Alexandra Hospital, Nephrology; University of Queensland, Australasian Kidney Trials Network Christian, Martin; Nottingham Childrens Hospital, Paediatric Nephrology Hamiwka, Lorraine; Alberta Children's Hospital, Pediatric Nephrology Ryan, Jessica; Monash Medical Centre Clayton, Nephrology Sinha, Aditi; All India Institute of Medical Sciences, Pediatric Nephrology Wong, Germaine; The University of Sydney School of Public Health, Centre for Kidney Research; Children's Hospital at Westmead Centre for Kidney Research, Centre for Kidney Research Craig, Jonathan; Flinders University Faculty of Medicine Nursing and Health Sciences, College of Medicine and Public Health, Groothoff, Jaap; Emma Childrens' Hospital UMC, Paediatric Nephrology Tong, Allison; The University of Sydney School of Public Health, Centre for Kidney Research; Children's Hospital at Westmead Centre for Kidney Research, Centre for Kidney Research
Primary Subject Heading:	Renal medicine
Secondary Subject Heading:	Renal medicine, Qualitative research, Patient-centred medicine, Paediatrics
Keywords:	Chronic renal failure < NEPHROLOGY, Dialysis < NEPHROLOGY, Renal transplantation < NEPHROLOGY, Paediatric nephrology < NEPHROLOGY

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60





I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our [licence](#).

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which [Creative Commons](#) licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22

**Perspectives on life participation by young adults with chronic kidney disease:
an interview study**

Jasmijn Kerklaan, MD^{1,2,3}, Elyssa Hannan, BPsych (Hons)^{1,2}, Camilla S Hanson, PhD^{1,2}, Chandana Guha, M.A.^{1,2}, Yeoungjee Cho, PhD^{4,5}, Martin Christian, MD⁶, Lorraine Hamiwka, MD⁷, Jessica Ryan, PhD⁸, Aditi Sinha, MD⁹, Germaine Wong, PhD^{1,2}, Jonathan C Craig, PhD¹⁰, Jaap Groothoff, PhD³, Allison Tong, PhD^{1,2}

23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52

Author affiliations

¹Sydney School of Public Health, The University of Sydney, Sydney, NSW, Australia

²Centre for Kidney Research, The Children's Hospital at Westmead, Westmead, NSW, Australia

³Department of Pediatric Nephrology, Emma Children's Hospital, Academic Medical Center, Amsterdam, The Netherlands

⁴Department of Nephrology, Princess Alexandra Hospital, Brisbane, Australia

⁵Australasian Kidney Trials Network at the University of Queensland

⁶Department of Paediatric Nephrology, Nottingham Children's Hospital, Nottingham, UK

⁷Division of Pediatric Nephrology, Alberta Children's Hospital, University of Calgary, Calgary, Alberta Canada

⁸Department of Nephrology, Monash Medical Centre, Melbourne, Australia

⁹Division of Nephrology, Department of Pediatrics, All India Institute of Medical Sciences, India

¹⁰College of Medicine and Public Health, Flinders University, Adelaide, South Australia, Australia

53
54
55
56
57
58
59
60

Corresponding author:

Jasmijn Kerklaan

Centre for Kidney Research, The Children's Hospital at Westmead, Westmead, NSW 2145, Sydney,

1 Australia

2 Phone: + 31 6 53142075

3 Email: kerklaan.j@gmail.com

4
5
6
7 **Wordcount (body):** 4592

8
9
10
11 **Keywords:** chronic kidney disease, young adults, life participation, dialysis, transplant

12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

For peer review only

Abstract

Objective: To describe the perspectives on life participation by young adults with childhood-onset chronic kidney disease (CKD).

Design: Semi-structured interviews; thematic analysis

Setting: Multiple centres across six countries (Australia, Canada, India, United Kingdom, United States and New-Zealand)

Participants: Thirty young adults aged 18-35 years diagnosed with CKD during childhood

Results: We identified six themes: struggling with daily restrictions (debilitating symptoms and side effects, giving up valued activities, impossible to attend school and work, trapped in a medicalized life, overprotected by adults, and cautious to avoid health risks); lagging and falling behind (delayed independence, failing to keep up with peers, and socially inept); defeated and hopeless (incapacitated by worry, an uncertain and bleak future, unworthy of relationships, and low self-esteem and shame); reorienting plans and goals (focusing on the day to day, planning parenthood, and forward and flexible planning); immersing oneself in normal activities (refusing to miss out, finding enjoyment, determined to do what peers do, and being present at social events); and striving to reach potential and seizing opportunities (encouragement from others, motivated by the illness, establishing new career goals, and grateful for opportunities).

Conclusions: Young adults encounter lifestyle limitations and missed school and social opportunities as a consequence of developing CKD during childhood and as a consequence lack confidence and social skills, are uncertain of the future, and feel vulnerable. Some re-adjust their goals and become more determined to participate in “normal” activities to avoid missing out. Strategies are needed to improve life participation in young adult ‘graduates’ of childhood CKD and thereby strengthen their mental and social wellbeing and enhance their overall health.

Strengths and limitations of this study

- Semi-structured interviews were conducted with young adults aged 18-35 years diagnosed with CKD during childhood, who were purposively sampled across six countries to obtain in-depth and diverse data on their perspectives on life participation.
- We conducted interviews until data saturation.
- Participants were all interviewed in English language and most participants were from high-income countries, therefore the transferability of the findings to other populations and settings is uncertain.
- Few participants were receiving dialysis at the time of the study though most of the participants had been on dialysis previously and discussed their past experiences.

Funding statement

This project is supported by a National Health and Medical Research Council Program Grant (ID 1092957). The funding organizations had no role in the design and conduct of the study; collection, management, analysis and interpretation of the data; preparation, review, or approval of the manuscript.

Competing interests statement

The authors do not have any competing interests or conflicts of interest to declare.

INTRODUCTION

Chronic kidney disease (CKD) in children is associated with increased mortality and may lead to impaired physical, social, and cognitive functioning¹⁻⁶. These challenges undermine the ability of children with CKD to achieve developmental milestones, autonomy, and independence, which can in turn limit successful participation in society during adulthood⁷⁻⁹. Young adults with childhood-onset of CKD have reported difficulties and delays in attaining educational, vocational and relationship goals, and are less likely to be employed than the age-matched general population^{10,11}.

Through a global consensus process that involved over 700 patients, caregivers and health professionals from more than 70 countries, the Standardised Outcomes in Nephrology – Children and Adolescents (SONG-Kids) initiative established life participation as the most important patient-reported outcome for children with CKD¹²⁻¹⁴. Where quality of life is defined as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns¹⁵. The concept of life participation is more specific and is defined as the ability to participate in meaningful activities that provide a sense of fulfillment, enjoyment, control and hope¹⁶. For children with CKD, meaningful activities include study, sport, social and leisure activities^{17,18}. Life participation is often restricted by the symptoms, side-effects, and treatment burden associated with CKD, and this has long-term consequences in young adulthood^{7,8,19,20}.

There is increasing recognition of the need to address the ability to participate in life^{10,20}, as this may also impact on motivation for self-management, coping, and treatment satisfaction. However, little is known about patients' perspectives on the meaning and impact of childhood CKD on 'life participation'. The aim of this study was to describe the perspectives of young adults with childhood-onset CKD on life participation, to inform interventions and clinical care and ultimately to improve health outcomes for patients with CKD.

METHODS

1
2 We followed the Consolidated Criteria for Reporting Qualitative Health Research (COREQ) to report this
3
4 study²¹ (Supplementary File 1).
5
6
7
8

9 **Participant Selection and Setting**

10
11 Participants were eligible to participate if they were English-speaking, aged from 18 to 35 years old, and
12
13 diagnosed with CKD prior to the age of 18 years. We included any cause of kidney disease and treatment
14
15 stage of CKD (CKD Stage 1-5 (not receiving kidney replacement therapy), dialysis, or transplant). Those
16
17 determined to be medically unsuitable by their clinician were excluded. Participants were recruited through
18
19 the SONG network using standardized invitation emails and by clinicians from centres across Australia,
20
21 Canada, India, United Kingdom and United States. Ethics approval was obtained from all participating sites
22
23 listed in Supplementary File 2. We applied a purposive sampling strategy to ensure a diverse range of
24
25 demographic and clinical characteristics.
26
27
28
29
30
31

32 **Data collection**

33
34 The interview guide was developed based on the literature on life participation and discussion among the
35
36 research team^{14,22} (Supplementary File 3). The questions focused on the meaning and impact of childhood
37
38 CKD on life participation during childhood and in young adulthood. From September to November 2019
39
40 author JK (a female medical student, who completed training in qualitative research) conducted one semi-
41
42 structured interview with each participant face-to-face at a venue as preferred by the participant, or by video
43
44 conference using zoom. There were no prior relationships established between JK and the participants. We
45
46 conducted interviews until we reached data saturation, that is, when no new concepts on life participation
47
48 were raised after three consecutive interviews. All the interviews were digitally audio-recorded and
49
50 transcribed. No fieldnotes were taken.
51
52
53
54
55
56
57

58 **Data Analysis**

59
60 The transcripts were imported into HyperRESEARCH (version 4.0.3) software. Using thematic analysis, JK

1 coded line-by-line all meaningful segments of text in the transcripts to inductively identify concepts, which
2 were grouped into initial themes and subthemes. We identified patterns and links among themes to develop a
3 thematic schema. To ensure the themes captured the breadth and depth of the data, these were discussed
4 with EH, CH and AT, who also read the transcripts, and participants were emailed a copy of the preliminary
5 findings and invited to provide comments. Any additional perspectives received were integrated into the
6 final analysis.
7
8
9
10
11
12

16 **Patient and Public Involvement**

17 The topic of life participant was identified by patient as a critically important outcome through the global
18 Standardised Outcomes in Nephrology – Children and Adolescents (SONG-Kids) Initiative^{12,17,18}. Patients
19 were directly involved in the study as participants in the interviews. Author CG is a caregiver and also a
20 member of the SONG-Kids Steering Committee who was involved in the planning and design of the study.
21 She advised on the study protocol including the data collection (e.g. interview guide), and was involved in
22 the interpretation of the data. Patients were not involved in the recruitment and were not involved in
23 conducting the interviews. Participants were emailed a copy of the preliminary findings and invited to
24 provide comments. Any additional perspectives received were integrated into the final analysis.
25
26
27
28
29
30
31
32
33
34
35
36
37
38

39 **RESULTS**

44 **Study Participants**

45 Overall, 30 young adults from Australia (n=16), Canada (n=5), India (n=4), United Kingdom (n=3), United
46 States (n=1) and New-Zealand (n=1) were included. They were between 18 to 32 years of age (mean 23.4
47 years, SD 4.0), and 20 (67%) were female. Non-participation (3) was due to refusal, illness, or inability to
48 schedule an interview after three attempts. The participant characteristics are shown in Table 1. The average
49 age at diagnosis was 7.7 years (SD 5.3). Seven (23%) participants were not receiving kidney replacement
50 therapy, two (7%) were receiving dialysis, and 21 (70%) had a kidney transplant. The average duration of
51 the interview was 53 minutes, with 14 interviews (47%) were conducted face to face. A parent was present
52
53
54
55
56
57
58
59
60

1 in five interviews (17%).
2
3
4

5 **Themes**

6

7 We identified six major themes: struggling with daily restrictions, lagging and falling behind, defeated and
8 hopeless, reorienting plans and goals, immersing oneself in normal activities, and striving to reach potential
9 and seizing opportunities. Each theme is expounded by subthemes.
10
11

12
13
14 Young adults who grew up with CKD struggled with daily restrictions, felt defeated and hopeless, and
15 lagging behind in their studies and other life goals. They had to give up valued activities, lacked confidence
16 and social skills, were uncertain of the future, and felt vulnerable. Some had to reorient their plans and goals.
17
18
19 Some participants initially struggled with this then overcame these struggles and re-adjusted their goals.
20
21
22 They immersed themselves in “normal” activities, refusing to miss out and were determined to do what
23 their peers could do. Some strived to reach potential and seize opportunities. Figure 1 depicts how the
24 themes relate to each other. Selected quotations to support each theme are provided in Table 2.
25
26
27
28
29
30
31
32
33
34

35 **Struggling with daily restrictions**

36
37 *Debilitating symptoms and side effects:* Symptoms and side effects such as infections, tiredness, and pain
38 limited the participants’ day-to-day activities. Fatigue made them “too tired to do anything”, and “unable to
39 get up in the morning”. For some, swelling impaired their mobility – “I couldn’t move because of my
40 swollen ankles”. Specific side-effects of immunosuppression, including weight gain, osteoporosis, hair
41 growth, and cognitive impairment restricted daily activities and prevented them from excelling (e.g. sports)
42 and caused some to drop out of college/university.
43
44
45
46
47
48
49

50
51
52
53 *Giving up valued activities:* Some felt forced to stop doing things they enjoyed, particularly sports including
54 swimming, football and rugby – “the [doctors] told me to quit the team”. They resented having to forgo
55 activities they valued – “I hated that I wasn't well enough to go to my dance school and I pretty much gave
56 up dancing.” Some had to refrain from foods they liked because of the dietary restrictions, or were
57
58
59
60

1 disappointed about being unable to travel – “I'd rather backpack, I'd rather go to a random country, but I
2 can't.”
3
4
5
6

7 *Impossible to attend school and work:* Attending school was “a big juggling act”, and some missed years of
8 education. Being too tired, unwell, and having to do dialysis or undergo surgery had prevented them from
9 attending school. Some felt self-conscious and wanted to stay home – “I was physically uncomfortable,
10 because of tubes sticking out of my stomach and chest. I just wanted to be home all the time”. One
11 participant was home schooled for over a year because of the risk of infection. Some had to take time off
12 work because of treatment.
13
14
15
16
17
18
19
20
21
22

23 *Trapped in a medicalized life:* The frequent and lengthy hospital appointments, dialysis regimen, surgeries
24 and having to take medications consumed their childhood. They were not allowed to go to school camp or
25 sleepovers because they had tubes and lines and needed to remain close to the hospital in case they needed
26 medical attention – “I am always going to have to be tied to the hospital because that's my lifeline, for
27 medications, blood tests, doctor appointments, checkups. It's always going to be at the forefront of my life.”
28 For patients receiving dialysis, they were “stuck to the machine.” Some could not spend the night with their
29 partner because they had to be home to do peritoneal dialysis. One participant mentioned that having
30 multiple surgeries (“20 surgeries in 21 months”) precluded them from educational and social activities.
31 Some participants felt “left to their own devices” after kidney transplant because they had been
32 “institutionalized” while on dialysis.
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Overprotected by adults: Some believed that overprotectiveness by adults inhibited their ability to live life
freely and with confidence – “Because they [my parents] were protective of me, I became a bit fearful, I
became scared of a lot of things.” Some were made to wear a medical mask or remain inside their house for
no apparent medical reason. Some also felt that doctors and teachers kept them “in a bubble” by advising
them against playing sports or travelling – “I've talked to Dr. X about it, but because his other patients have
gotten really sick, he's telling me not to go [travel to Asia].”

1
2
3 *Cautious to avoid health risks:* Some were cautious and vigilant to avoid health risks to avoid being blamed
4 for getting sick. They always considered the consequences of their behavior and questioned, “is this going to
5 affect my kidney?” They were not able to drink alcohol or travel to certain places. They were constantly
6 planning ahead for simple tasks such as what they would eat and drink. Participants from India mentioned
7 being particularly careful not to get an infection when leaving the house.
8
9
10
11
12
13
14
15

16 **Lagging and falling behind**

17
18 *Delayed independence:* Participants felt they lacked the foundations for developing into independent adults
19 and were unprepared for the future. Those who were on dialysis during childhood felt their lives had been
20 put on hold – “I have missed three years of my life”. Some had to live with their parents because they
21 depended on them for financial support and were concerned about their ability to sustain employment and
22 afford housing during periods of ill health – “I’d like to move out, but if anything serious happens and I
23 can’t work, I can’t pay for the place anymore.” They felt their ability to gain independence was limited
24 because they had “grown up with pretty much everything being done for me”.
25
26
27
28
29
30
31
32
33
34
35
36

37 *Failing to keep up with peers:* Some were too tired and unable to concentrate and were often “falling asleep
38 in school”. They missed learning the basics and felt unable to reach their potential – “Now I experience
39 difficulty while studying... if my basics were better, I would have scored higher [in mathematics].” Some
40 were upset as they watched their classmates graduate while they were left behind – “I was studying
41 engineering and I watched a lot of my friends go on and graduate from that program.” This led them to feel
42 lacking in intelligence and skills compared with their peers.
43
44
45
46
47
48
49
50
51
52

53 *Socially inept:* Having missed out on interacting with friends because of childhood CKD, some felt they
54 lacked social skills as a young adult and felt “awkward” and suffered “social anxiety” – “I’ve missed out on
55 like the social side to life as a kid ... I have social anxiety. I struggle with big crowds and the work
56 Christmas party I don’t go to.” Some felt alone and isolated. One participant was confined at home during
57
58
59
60

1 childhood to avoid infection – “No one could really come over. I was just in my room for a little bit over a
2 year.” Some withdrew from others because they “didn’t feel like being around people” to avoid stigma, pity
3 and having to explain themselves. Some lost friends or felt forgotten by them or became distanced from
4 former friends because CKD had changed who they were and what they could do.
5
6
7
8
9

10 **Defeated and hopeless**

11
12 *Incapacitated by worry:* Participants worried about their health and “dying young” – “I feel like I’m
13 definitely going to die younger than a lot of my family”. Some participants, not yet on kidney replacement
14 therapy worried about “having to rely on a [dialysis] machine in the future”. Transplant recipients were
15 concerned about graft failure. Some were “living their lives on hold” because of the constant daily worries –
16 “I get in a bad headspace and worrying about things that haven’t even happened yet [transplant failure]”.
17
18
19
20
21
22
23
24

25
26
27 *An uncertain and bleak future:* At times, when “they didn’t see the point anymore,” they wanted to give up –
28 “When the doctor said, ‘Oh you might need to be on dialysis.’ It kind of just made me give up in school”.
29 Some participants, particularly those with genetic kidney disease, braced themselves for deteriorating health
30 and consequent restrictions – “My life participation is going to decline and that I won’t be able to do things”.
31 Participants who did not know the cause of their kidney disease felt “insecure” about the future.
32
33
34
35
36
37
38
39
40

41
42 *Unworthy of relationships:* Some worried about “ending up alone,” because they felt they “weren’t good
43 enough” for a partner and thought “no one would ever love them”. One participant from India explained: “if
44 you have to buy an apple, you will take a fresh one, not the one that has a hole in the middle. They will
45 choose the healthy one [for an arranged marriage]”. Another recalled their partner breaking up with them
46 because of kidney disease – “he said, ‘I want an active future. I don't want a future where I'm in and out of
47 hospital with someone’”.
48
49
50
51
52
53
54
55
56

57
58 *Low self-esteem and shame:* Childhood CKD impaired self-esteem through to adulthood – “I am still not
59 fully confident about myself, and this would not have happened [if I didn’t have CKD as a child].” Some
60

1 became “upset looking in the mirror”, felt “ashamed” or “avoided going out” because of CKD and
2 treatment-related weight gain, stretch marks or scars – “I didn't want to do anything because I had fluids
3 [swelling] everywhere and I just wanted to be normal”. Some reported being bullied by others because of
4
5 CKD.
6
7
8
9

10 11 **Reorienting plans and goals**

12
13
14 *Focusing on the day to day:* Thinking about the future was difficult because of the unpredictability of the
15 kidney disease, so instead participants focused on “living in the present” and “doing a day at a time”. Some
16 explained that whenever they planned their future, “it never seemed to happen” [going back to school or
17 work]. Patients who had been on dialysis formed a habit of concentrating on getting through each day.
18
19
20
21
22

23
24
25 *Planning parenthood:* Some felt pressured to think about parenthood at a young age, when they were not
26 ready to have a family, and said doctors advised to “have children as soon as possible”, “get their eggs
27 harvested” or advised that “it was going to be more difficult due to previous treatments and medication.”
28 One participant said, “to become a father I will have to do IVF”. Some feared the possibility of genetic
29 transmission and causing their child to suffer – “I will never have my own kids, because I don't know how I
30 got the disease. Because if he or she ends up having a problem, I will be blaming myself”. Some women
31 were concerned about jeopardizing their kidney health (or graft) by becoming pregnant.
32
33
34
35
36
37
38
39
40
41
42
43

44 *Forward and flexible planning:* Participants had to think ahead, change goals or make adjustments to their
45 lives because of kidney disease, which was frustrating though some learned to accept this. Some transplant
46 recipients tried to find part-time work in case they lost their graft. Participants with fluid and diet restrictions
47 would “save” their intake so they could eat and drink more freely at social events – “I will not eat potassium
48 foods and I'll be careful today with water, so when I get to the party, I can actually have a soft drink”. Some
49 established daily and travel schedules around the medication regimen.
50
51
52
53
54
55
56
57
58
59
60

Immersing oneself in normal activities

1 *Refusing to miss out:* Some strived to do “normal” things refusing to let the CKD stop them. They “didn’t
2 see themselves as unable to do things”. Some made adjustments to enable them to play sports – “We did
3 five-a-side football, which I was able to do because they made like a special shield that went over the
4 kidney”. They were adamant not to fixate on restrictions.
5
6
7
8
9

10
11 *Finding enjoyment:* Some learned to enjoy life more and to “appreciate the little things” because of the
12 kidney disease, making every effort to “enjoy every day and have fun”. During dialysis, patients developed
13 new hobbies or invited friends to visit and play card games.
14
15
16
17
18
19

20
21 *Determined to do what peers can do:* Some were determined to do what their peers could do. During
22 childhood, they desired “to be normal” and to “be able to do everything everyone else did,” which also
23 included drinking – “I still went out and drank, because I wanted to be normal”.
24
25
26
27
28
29

30 *Being present at social events:* Being able to socialize and “hang out” with friends and family was important
31 – “[kidney disease] doesn’t impact me that it stops me from going out and having a social life”. At times,
32 they had, “friends joining my dialysis session” or “parents joining a school camp”.
33
34
35
36
37
38

39 **Striving to reach potential and seizing opportunities**

40
41 *Encouragement from others:* Participants talked about how “not being treated differently or as if they
42 couldn’t do things” helped them stay motivated and not to feel like a patient. Some found it helpful to meet
43 others with kidney disease, “people that understood” – “that was the point where my whole attitude towards
44 everything changed, because I realized that I wasn’t alone and I realized that actually people were coping
45 with it”.
46
47
48
49
50
51
52
53

54
55 *Motivated by the illness:* For some, CKD gave them “a reason to do things” and motivated them “to make
56 healthier choices in life”. Some made it their mission to be as fit as possible to “slow down” the disease.
57
58 Some were inspired to support and mentor other children and young adults with kidney disease – “I’m there
59
60

1 for the new generation, to help them cope and be that inspiration”.

2
3
4
5 *Establishing new career goals:* Some changed career path because they felt they lacked education, had
6 health problems or wanted to avoid the risk of infection – “I’d probably go into something with childcare.
7 But because of infection and stuff, that’s probably not a good idea”. Others redirected their goals to pursue
8 work in healthcare because the disease made them realize they wanted to be a “doctor, “nurse” or “social
9 worker” – “it made me realize that I wanted to be a nurse. I suppose that's a good thing out of a bad
10 situation”.

11
12
13
14
15
16
17
18
19
20
21 *Grateful for opportunities:* Some participated in activities (e.g. world transplant games, cruises) that were
22 organized by the hospitals, support groups and charity organizations. – “I probably never would have
23 experienced that [if I didn’t have kidney disease]”. Having experienced illness in childhood made them
24 grateful for what they were able to do now as young adults – “when I go on a hike or to the gym, I’m like, I
25 am so lucky. I’m so grateful that I can do these things because I wasn’t able to do it before”.

32 33 34 **DISCUSSION**

35
36
37
38
39 Young adults with childhood-onset CKD struggled with day-to-day restrictions and limitations in their
40 ability to work, study and participate in social and leisure activities because of symptoms and side effects
41 and burden of treatment, the need to minimize health risks, and being overprotected by adults. They felt
42 unable to keep up with their peers and attributed social anxiety and feelings of inferiority to missing out on
43 social interaction and school during childhood. Some were frustrated in having to remain dependent on their
44 parents and being unable to gain independence, move out of home, and establish relationships, feeling
45 defeated and hopeless about their future. These challenges meant they had to reorient their plans and goals.
46 Some became determined to immerse themselves in normal activities and to take every opportunity to do
47 what their peers were able to do. They reflected that childhood CKD gave them opportunities they would not
48
49
50
51
52
53
54
55
56
57
58
59
60

1 have had otherwise (e.g. participating in transplant games), or motivated them to establish career goals, for
2 example in counseling and nursing.
3
4
5
6

7 These findings were broadly consistent across the different demographic and clinical characteristics of
8 participants, and their care settings. However, we noted some differences by age group, age at diagnosis,
9 country and experience of dialysis. Younger participants reported difficulties with attending school/study
10 and keeping up with peers, dropping out of higher education, and were concerned about missing social
11 events. Older participants were focused on being able to work and establish a career path given their
12 uncertain prognosis, and seemed to contemplate longer term consequences. Those who were diagnosed with
13 kidney disease at an older age found it more difficult to give up valued activities such as sport. There were
14 some specific concerns such as infection, identified by participants in India, which may be attributable to the
15 higher risk²³. They also worried about being “unsuitable” for arranged marriage. Participants who had been
16 on dialysis for a longer period of time during childhood seemed to face, to a greater extent, loss of friendship
17 and inability to participate in recreational activities.
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33

34 Our findings reflect those of previous studies²⁴, which have also found that young adults with childhood-
35 onset CKD report difficulties with education, employment and social relationships²⁵⁻²⁸, and perceive that
36 their lives are “on hold”^{29,30}. These problems of life participation have also been documented in studies in
37 young people diagnosed with other childhood chronic conditions, including cystic fibrosis, hematological
38 and autoimmune disease, who also feel impaired in their social interactions and capacity to keep up with
39 peers³¹ and have lower life satisfaction³². Our study further reveals that young adults believe that missing
40 school and social opportunities, and being “overprotected” during childhood caused them to lack the
41 fundamental skills and confidence for social interaction, and develop independence to participate in life as
42 autonomous adults. Consequently, this instilled vulnerability, uncertainty and fear of their future in terms of
43 day-to-day functioning, and setting and pursuing educational and career goals.
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1 This study was multinational and offers in-depth insights gained from a reasonably diverse group of young
2 adults with childhood-onset CKD. We achieved data saturation and used investigator triangulation to ensure
3 that the themes reflected the breadth and depth of the data. However, there are some potential limitations.
4
5 Most participants were from high-income countries, therefore the transferability of the findings to other
6
7 populations and settings is uncertain. The sample was skewed in relation to gender with only one third of the
8
9 population being male, while CKD affects more male. This could be a weakness we want to acknowledge.
10
11 Only two patients were receiving dialysis at the time of the study though most of the participants had been
12
13 on dialysis previously and discussed their past experiences. Some interviews were conducted with parents
14
15 present, but we are unable to determine if this inhibited open responses.
16
17
18
19
20
21
22

23 There is a need to improve life participation in patients with childhood CKD and strategies that encompass
24
25 psychosocial, educational and vocational support delivered in both the pediatric and adult healthcare settings
26
27 are suggested. A multidisciplinary model of care involving nephrologists, psychologists, social workers and
28
29 occupational therapists may help to bring awareness and address the barriers to life participation. For
30
31 example by managing unresolved anxiety, uncertainty and fears to strengthen confidence and self-esteem in
32
33 participating in activities, establishing relationships, and decision-making about parenthood. Identifying and
34
35 building social networks may motivate and support young patients to develop independence, autonomy, and
36
37 determination to engage in life activities and work towards their goals. Online support groups and camps
38
39 could promote a sense of normality and social inclusion³³. School-based interventions, that includes
40
41 advocacy for patients to increase understanding among their peers and individual tutoring may improve
42
43 social and educational outcomes³⁴. Social workers and potentially peer navigators, could assist young adults
44
45 with finding employment, and accessing social benefits and housing²⁷. Given the medical, ethical, and
46
47 emotional complexities of fertility and parenthood in CKD, we suggest counselling that is sensitive to
48
49 patients' preparedness and life priorities^{35,36}.
50
51
52
53
54
55
56

57 Rehabilitation programs may have potential in young people with chronic kidney disease. Trials of
58
59 cognitive-based problem-solving strategies improved level of activity and life participation in children with
60

1 other conditions including development coordination disorder and cerebral palsy^{37,38}. This study used a
2 strategy comprised of identifying occupational performance problems by the children and their parents, and
3 conducting weekly group sessions for 10 weeks, along with 15 minutes per day of home activities. Physical
4 rehabilitation programs for adults on dialysis have been shown to improve the ability to perform daily
5 activities and physical functioning³⁹. This particular program comprised of an assessment of level of activity
6 and functional ability, collaborative goal setting that accounted for patient's preferences and lifestyle,
7 problem solving to address barriers to physical activity, and identifying social supports to maintain an
8 increased level of activity. Similar rehabilitation program may be adapted for young people with chronic
9 kidney disease, focused on relevant activities in this population.
10
11
12
13
14
15
16
17
18
19
20
21
22

23 Whilst the need to improve life participation in young adults with childhood CKD is evident, trials of
24 interventions to improve the aspects of life participation prioritized by our participants are sparse.
25 Recognizing that patient involvement in research improves the relevance, implementation and uptake of
26 research⁴⁰, we suggest that future studies should involve patients in co-designing and evaluating
27 interventions. Also, we recognize that assessing this outcome may be challenging as there is currently no
28 patient-reported outcome measure for life participation validated for use in this population. Further work is
29 needed to identify or establish a patient-reported outcome that includes the dimensions of life participation
30 that are important to children and young adults with CKD.
31
32
33
34
35
36
37
38
39
40
41
42
43

44 Young adults encounter lifestyle limitations and missed school and social opportunities during childhood
45 CKD and as a consequence feel lacking in confidence and social skills, uncertain of the future, and
46 vulnerable. Some re-adjust their goals and become more determined to participate in "normal" activities to
47 avoid missing out. Strategies and interventions are needed to improve life participation in young adults with
48 childhood CKD and thereby strengthen their mental and social wellbeing and enhance overall health.
49
50
51
52
53
54
55
56
57
58
59
60

Acknowledgements

We thank all participants for sharing their interesting and thoughtful perspectives in this study.

Author contributions

Research idea and study design: AT, JK; data acquisition: JK; data analysis/interpretation: JK, EH, CH, AT; supervision or mentorship: AT, JG, JCC. AT, JG, JCC, YC, CG, MC, LH, JR, AS and GW contributed important intellectual content during manuscript drafting or revision and accepts accountability for the overall work by ensuring that questions pertaining to the accuracy or integrity of any portion of the work are appropriately investigated and resolved.

Ethics approval

All participants provided written informed and voluntary consent. The study was approved by The University of Sydney, The Sydney Children's Hospital Network (Westmead, Sydney, NSW, Australia), Royal Children's Hospital (Monash Health, Melbourne, VIC, Australia) and Princess Alexandra Hospital (Brisbane, QLD, Australia). Furthermore, The University of Sydney (Australia) provided ethics approval to recruit through the international SONG Initiative Patient Network. Patients from any country can voluntarily register to receive information about opportunities to participate in SONG-related research. The network is hosted on the University of Sydney server. Participants outside of Australia were not recruited from hospitals/institutions.

Data sharing

No additional data are available.

References

1. Gerson AC, Wentz A, Abraham AG, et al. Health-related quality of life of children with mild to moderate chronic kidney disease. *Pediatrics* 2010;125:e349-e57.
2. Tong A, Tjaden L, Howard K, Wong G, Morton R, Craig JC. Quality of life of adolescent kidney transplant recipients. *J Pediatr* 2011;159:670-5. e2.
3. Lande MB, Gerson AC, Hooper SR, et al. Casual blood pressure and neurocognitive function in children with chronic kidney disease: a report of the children with chronic kidney disease cohort study. *Clin J Am Soc Nephrol* 2011;6:1831-7.
4. Haavisto A, Korkman M, Holmberg C, Jalanko H, Qvist E. Neuropsychological profile of children with kidney transplants. *Nephrol Dial Transplant* 2011;27:2594-601.
5. Hooper SR, Gerson AC, Johnson RJ, et al. Neurocognitive, social-behavioral, and adaptive functioning in preschool children with mild to moderate kidney disease. *J Dev Behav Pediatr* 2016;37:231.
6. Thys K, Schwering KL, Siebelink M, et al. Psychosocial impact of pediatric living-donor kidney and liver transplantation on recipients, donors, and the family: a systematic review. *Transpl Int* 2015;28:270-80.
7. Groothoff J, Grootenhuis M, Dommerholt A, Gruppen M, Offringa M, Heymans H. Impaired cognition and schooling in adults with end stage renal disease since childhood. *Arch Dis Child* 2002;87:380-5.
8. Groothoff JW, Grootenhuis MA, Offringa M, Stronks K, Hutten GJ, Heymans HS. Social consequences in adult life of end-stage renal disease in childhood. *J Pediatr* 2005;146:512-7.
9. Rocha S, Fonseca I, Silva N, et al. Impact of pediatric kidney transplantation on long-term professional and social outcomes. *Transplant Proc* 2011;43:120-4.
10. Tjaden LA, Grootenhuis MA, Noordzij M, Groothoff JW. Health-related quality of life in patients with pediatric onset of end-stage renal disease: state of the art and recommendations for clinical practice. *Pediatr Nephrol* 2016;31:1579-91.
11. Mellerio H, Alberti C, Labèguerie M, et al. Adult social and professional outcomes of pediatric renal transplant recipients. *Transplantation* 2014;97:196-205.
12. Hanson CS, Gutman T, Craig JC, et al. Identifying Important Outcomes for Young People With CKD and Their Caregivers: A Nominal Group Technique Study. *Am J Kidney Dis* 2019.
13. Tong A, Samuel S, Zappitelli M, et al. Standardised Outcomes in Nephrology—Children and Adolescents (SONG-Kids): a protocol for establishing a core outcome set for children with chronic kidney disease. *Trials* 2016;17:401.
14. Standardised Outcomes in Nephrology – Children and Adolescents (SONG-Kids) available at <https://songinitiative.org/projects/song-kids/> accessed 1st December 2019. 2019.
15. World Health Organization available at <https://www.who.int/healthinfo/survey/whoqol-qualityoflife/en/> accessed 23th of July 2020. 2020.

16. Ju A, Josephson MA, Butt Z, et al. Establishing a core outcome measure for life participation: A standardized outcomes in nephrology-kidney transplantation consensus workshop report. *Transplantation* 2019;103:1199-205.
17. Logeman C, Guha C, Howell M, et al. Developing Consensus-Based Outcome Domains for Trials in Children and Adolescents With CKD: An International Delphi Survey. *Am J Kidney Dis* 2020.
18. Hanson CS, Craig JC, Logeman C, et al. Establishing core outcome domains in pediatric kidney disease: report of the Standardized Outcomes in Nephrology–Children and Adolescents (SONG-KIDS) consensus workshops. *Kidney Int* 2020.
19. Groothoff J. Long-term outcomes of children with end-stage renal disease. *Pediatr Nephrol* 2005;20:849-53.
20. Tjaden LA, Vogelzang J, Jager KJ, et al. Long-term quality of life and social outcome of childhood end-stage renal disease. *J Pediatr* 2014;165:336-42. e1.
21. Booth A, Hannes K, Harden A, Noyes J, Harris J, Tong A. COREQ (consolidated criteria for reporting qualitative studies). *Guidelines for reporting health research: A user's manual* 2014:214-26.
22. World Health Organization. *International classification of functioning, disability and health: ICF*: Geneva: World Health Organization; 2001.
23. Cortes-Santiago N, Leung DH, Castro E, Finegold M, Wu H, Patel KR. Hepatic Steatosis Is Prevalent Following Orthotopic Liver Transplantation in Children With Cystic Fibrosis. *J Pediatr Gastroenterol Nutr* 2019;68:96-103.
24. Hamilton AJ, Caskey FJ, Casula A, Ben-Shlomo Y, Inward CD. Psychosocial Health and Lifestyle Behaviors in Young Adults Receiving Renal Replacement Therapy Compared to the General Population: Findings From the SPEAK Study. *Am J Kidney Dis* 2019;73:194-205.
25. Tong A, Henning P, Wong G, et al. Experiences and perspectives of adolescents and young adults with advanced CKD. *Am J Kidney Dis* 2013;61:375-84.
26. Cura J. Interpreting transition from adolescence to adulthood in patients on dialysis who have end-stage renal disease. *Journal of renal care* 2012;38:118-23.
27. Murray PD, Dobbels F, Lonsdale DC, Harden PN. Impact of end-stage kidney disease on academic achievement and employment in young adults: a mixed methods study. *Journal of Adolescent Health* 2014;55:505-12.
28. Lewis H, Arber S. Impact of age at onset for children with renal failure on education and employment transitions. *Health*. 2015;19:67-85.
29. Crowley-Matoka M. Desperately seeking “normal”: the promise and perils of living with kidney transplantation. *Soc Sci Med* 2005;61:821-31.
30. Molzahn AE, Bruce A, Shields L. Learning from stories of people with chronic kidney disease. *Nephrol Nurs J* 2008;35:13.

- 1 31. Nap-van der Vlist MM, Kars MC, van der Sprenkel EEB, et al. Daily life participation in childhood
2 chronic disease: a qualitative study. *Arch Dis Child* 2019.
- 3 32. Matthie N, Hamilton J, Wells D, Jenerette C. Perceptions of young adults with sickle cell disease
4 concerning their disease experience. *J Adv Nurs* 2016;72:1441-51.
- 5 33. Allen C, Vassilev I, Kennedy A, Rogers A. Long-term condition self-management support in online
6 communities: a meta-synthesis of qualitative papers. *J Med Internet Res* 2016;18:e61.
- 7 34. Lansing L. Back to school for the child on long-term hemodialysis. *AANNT J* 1981;8:13.
- 8 35. Bramham K, Lightstone L. Pre-pregnancy counseling for women with chronic kidney disease. *J*
9 *Nephrol* 2012;25:450-9.
- 10 36. Wiles KS, Bramham K, Vais A, et al. Pre-pregnancy counselling for women with chronic kidney
11 disease: a retrospective analysis of nine years' experience. *BMC nephrol* 2015;16:28.
- 12 37. Cameron D, Craig T, Edwards B, Missiuna C, Schweltnus H, Polatajko HJ. Cognitive Orientation to
13 daily Occupational Performance (CO-OP): A new approach for children with cerebral palsy. *Phys Occup*
14 *Ther Pediatr* 2017;37:183-98.
- 15 38. Thornton A, Licari M, Reid S, Armstrong J, Fallows R, Elliott C. Cognitive orientation to (daily)
16 occupational performance intervention leads to improvements in impairments, activity and participation in
17 children with Developmental Coordination Disorder. *Disabil Rehabil* 2016;38:979-86.
- 18 39. Tawney KW, Tawney PJ, Hladik G, et al. The life readiness program: a physical rehabilitation
19 program for patients on hemodialysis. *Am J Kidney Dis* 2000;36:581-91.
- 20 40. Liabo K, Boddy K, Burchmore H, Cockcroft E, Britten N. Clarifying the roles of patients in research.
21 *BMJ* 2018;361:k1463.
- 22
- 23
- 24
- 25
- 26
- 27
- 28
- 29
- 30
- 31
- 32
- 33
- 34
- 35
- 36
- 37
- 38
- 39
- 40
- 41
- 42
- 43
- 44
- 45
- 46
- 47
- 48
- 49
- 50
- 51
- 52
- 53
- 54
- 55
- 56
- 57
- 58
- 59
- 60

Figure Legends

Figure 1. Thematic schema

For peer review only

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46

Table 1. Participant characteristics

Characteristics	N	(%)
Sex		
Men	10	(33)
Women	20	(67)
Age group (years)		
18-21	12	(40)
22-25	9	(30)
26-30	7	(23)
31-35	2	(7)
Country		
Australia	16	(55)
Canada	5	(17)
India	4	(13)
United Kingdom	3	(10)
United States	1	(3)
New-Zealand	1	(3)
Highest level of education		
Primary School	1	(3)
Secondary school, grade 10	4	(13)
Secondary school, grade 12	6	(20)
Tertiary, certificate/diploma	4	(13)
Tertiary, undergraduate/bachelor	13	(43)
Tertiary, Postgraduate/ Masters/PhD	2	(7)
Employment status		
Full time	6	(20)
Part time or casual	7	(23)
Student	13	(43)
Voluntary work	1	(3)
Not employed	4	(13)
Marital status		
Married	4	(13)
Partner (living together)	4	(13)
Partner (not living)	4	(13)
Divorced/separated	0	(0)
Single	18	(60)
Living with		
Parents/family	19	(63)
Housemates	2	(7)
Partner	7	(23)
By themselves	2	(7)
No. of children		
0	28	(93)
1	2	(7)

Clinical characteristics	N	(%)
Age at CKD diagnoses (years)		
Prenatal or at birth	2	(7)
0-5	7	(23)
6-10	9	(30)
11-15	8	(27)
16+	4	(13)
CKD diagnosis or cause		
Congenital abnormalities of kidney/urinary tract	7	(23)
Focal segmental glomerulosclerosis	4	(13)
Nephrotic Syndrome (cause not specified)	3	(10)
Polycystic kidney disease	3	(10)
Hemolytic Uremic Syndrome	2	(7)
Lupus Nephritis	2	(7)
Reflux Nephropathy	2	(7)
Granulomatosis with polyangiitis	1	(3)
Henoch Schönlein Purpura	1	(3)
Diabetic	1	(3)
Unknown	1	(3)
Other	3	(10)
Current CKD treatment stage		
Not on kidney replacement therapy	7	(23)
5D, hemodialysis	2	(7)
5D, peritoneal dialysis	0	(0)
5T, deceased donor kidney transplant	13	(43)
5T, living donor kidney transplant	8	(27)
Treatment during childhood*		
No kidney replacement therapy	15	
Hemodialysis	8	
Peritoneal dialysis	8	
Transplant	13	

Note: N = 30. Percentage may not total 100 due to rounding.

* = May not add up, because of possible multiple answers per person

Table 2. Selected participant quotations for each theme

Theme	Quotations
Struggling with daily restrictions	
Debilitating symptoms and side effects	I'd wake up and be totally fine and then by three o'clock in the afternoon, I couldn't walk because my ankles and my knees were so swollen with water. (F, 22-25) It was limiting in a lot of ways. I got sick a lot, with infections and colds. It seemed like everything knocked me down. And then I would deal with the HSP rash and then I had nephrotic syndrome and I actually went through chemo to treat the nephrotic syndrome, which caused me to drop out of college and it, it impacted my academics a lot and a lot of the things that I got to do.(F, 18-21,) The medications, they are really strong. They affect your memory, they affect your body, they affect you in every way. (F, 31-35)
Giving up valued activities	I did a lot of sports in my early teens. I did competitive swimming, football and rugby and I had to stop. I was devastated. (F, 18-21) What I wanted then was just to feel better so that I could go to school. I loved school. I've always been quite academic. I hated not being there. I hated that, I wasn't well enough to go to my dance school and I pretty much gave up dancing. (F, 22-25) My friends went to Europe, I couldn't go. Travel's probably the main thing. That was quite hard. (F, 26-30)
Impossible to attend school and work	I was physically uncomfortable, because of tubes sticking out of my stomach and chest. I just wanted to be home all the time. (F, 31-35) I'm juggling school, it's just a big juggling act at the moment. And even then, I'm still struggling cause sometimes I can't make it to school. Not because of my mental state. Just because I'm so tired. (M, 18-21)
Trapped in a medicalized life	Back then I had a lot of restrictions. I had catheters, Hickman lines and was fed via a peg tube (F, 26-30) Before, I was doing home hemo, I thought my life was ending because I had to be stuck with this machine, three times a week for hours. (F, 26-30) It's three times a week, five or six hours each day. It's just ridiculous. So much time. And then when you get off, you feel so drained and I couldn't really socialize much and everything. (F, 22-25) I kept going back and staying in hospital. For me that was a bit like escaping from the real world I guess. I guess you just get a bit institutionalized. (F, 22-25)
Overprotected by adults	I was able to, but my parents didn't let me go outside. They said: you should stay home and rest. (M, 18-21) I've talked to Dr. X about it, and he's like 'no,' because his other patients have gotten really sick, so that adds to my anxiety. I mean he's telling me not to go [travel to Asia]. (F, 26-30) After the transplant they told me 'maybe you shouldn't play netball because you could hit the kidney'. What some doctors tell you keeps you in a bubble if you follow it, I guess. (F, 18-21)
Cautious to avoid health risks	I'd absolutely love to go to Egypt. But they recommend live vaccines. I can't have that. And it's definitely not worth having the vaccine and getting ill from it. (F, 22-25) Always when I do something, there's a list that I go through in my head; how is this going to affect me and if it's going to be bad or positive or how it's going to affect my kidneys. (F, 18-21) I cannot go out drinking with friends or I can go and I'm the only one sitting with no drink, it feels stupid. (F, 22-25)
Lagging and falling behind	
Delayed independence	I missed out on a proper education. I feel like I've missed three years of my life, I feel like a 17-year-old stuck in a 19-year-old body. I feel like I'm too old for who I really am. I just feel like I'm not quite smart enough at the moment to be almost 20 years old. (M, 18-21) I'd like to move out, but if anything serious happens and I can't work, I can't pay for the place anymore. (M, 22-25) I think financially is mostly where it's been an issue. I feel like I'm dependent on either the government or my dad or even my fiancé sometimes, because I don't have the same education. I don't have a degree in order for me to get a good job. (F, 22-25)
Failing to keep up with peers	All my friends would go out after school and play out and all that kind of thing. I was never able to do that because I just didn't feel well enough. (F, 22-25) My friends are already graduated and at work and they look like they have a goal and I don't even know what I want and I'm already 25. (F, 22-25) I would always play hide and seek instead of tag because I didn't want people to make fun of me for not being able to run properly. (F, 22-25)

1	Socially inept	I'll exclude myself in situations where I can't do something or didn't feel comfortable. (M, 22-25)
2		I kind of withdrew from a lot of my friends. I think that I missed out on some social skills. Socially I feel kind of impeded. (F, 22-25)
3		I used to be sad too. I'd really kind of avoided hanging around with kids. (F, 22-25)
4		I feel a bit socially awkward, I don't know if it's because of my lack of social interactions when I younger. (M, 22-25)
5	Defeated and hopeless	
6	Incapacitated by worry	Because when you have kidney disease, it just feels like you're a prisoner versus normal. (F, 26-30)
7		Oh my gosh, I'm nearly halfway [estimated graft survival]. And you know that there's no say in that it's only 20 years or that it is definitely 20 years. It could be more, it could be less. You just don't know. But at that time it just got in my head that I was almost halfway [about the transplant]. (F, 18-21)
8		And then if your kidney was to fail then what? If you are a young mum and you have kids and everything. You can't afford to be in hospital again. (F, 22-25)
9		
10	An uncertain and bleak future	I understand that my life participation is going to decline and that I won't be able to do things and I'm going to have to compromise. (F, 18-21)
11		I think you can only have a couple of transplants because of the medication and because of the antibodies and all that kind of stuff. And each transplant works for like 10 years. I mean, you can do the counting. (F, 18-21)
12		
13		I'll probably say Brexit is one of them. We don't know what's going to happen. Cause I probably will be doing home dialysis and the supplies are all from European countries. (M, 26-30)
14		
15	Unworthy of relationships	I'm not in a relationship now. I had to like consider it with a guy and that's when it comes up. I feel like I don't want to burden people. (F, 26-30)
16		You put yourself down and you start thinking, would anyone ever love me because I have those problems. (F, 22-25)
17		It's a little bit hard to be friends with somebody who's a sick kid, which is tough to say, but I think it is harder to have a friend who's sick. (F, 18-21)
18		
19	Low self-esteem and shame	I have been on prednisone for six years now, so I have a moon face and it's caused me to gain weight. I was a lot skinnier before, I had a lot better self image. It's been really impactful. (F, 18-21)
20		It was hard at school because obviously I looked different. I had tubes sticking out of my stomach. I had to be careful how I sat, I had to be careful around other kids. Kids had no idea what it was. They'd make fun of you. (F, 26-30)
21		
22		I used to see girls of my age getting complimented by guys and the guys actually wanted to go out with them. So I used to feel really bad about that. (F, 22-25)
23		I think I am kind of a self-conscious person as well. So the symptoms of the prednisolone and the face blowing up and all that was a big issue for me. I was always conscious about that and the kids bullying and stuff like that. That was hard. (F, 22-25)
24		
25	Reorienting plans and goals	
26	Focusing on the day to day	Whenever I plan a future, it doesn't happen. Just planning short term. I'll be planning what I have to do in the evening and what I have to do tomorrow. (F, 22-25)
27		I've definitely learned to just kind of take every day as it comes and just see what happens. (F, 22-25)
28		
29		I feel like the transition from being in hospital for so long and coming out, it was really hard. In the hospital you had stress as well, but you're only stressed about; Oh, am I getting dialysis today? Am I going to cramp really bad today? Whilst now, I suddenly have to think about other stuff. (F, 22-25)
30		
31	Planning parenthood	Getting my eggs harvested so that, when I decide if I want children I can select ones without the PKD. (F, 18-21)
32		I had to change medications because it causes birth defects. So I had to do that and I just have these worries. Like what if I start to lose my kidney during pregnancy? Do I have to get back on dialysis? Is my child going to be okay? Am I going to pass anything down to my child? And that's if I can get pregnant. (F, 31-35)
33		
34		Being a father, I found out I have to stop my mycophenolate for three months and then I have to do IVF now. (M, 22-25)
35		We were told we had to have kids soon. So from not really hearing that before to hearing that straight away, we were quite a bit shocked. (F, 26-30)
36	Forward and flexible planning	I do find myself thinking, it would be beneficial to find something where if I have to go part time, I can still afford to live. I'll probably have to go part time at some point to accommodate dialysis. (F, 22-25)
37		
38		I didn't drink yesterday and I haven't drunk today just so I could drink this warm chocolate. (M, 18-21)
39		Before the diagnosis I was it really into track and after the diagnosis I was into rowing because I could sit down and do it. (F, 18-21)
40		
41		
42		
43		
44		
45		
46		

Immersing oneself in normal activities

- 1 Refusing to miss out I didn't see myself as unable to do things that they could. (F, 18-21)
 2 I still tried to do the things I wanted to do, while still being on hemodialysis. It didn't stop me from what I wanted to do. (F, 26-30)
 3 We did five-a-side football, which I was able to do because they made like a special shield that went over the kidney. (M, 26-30)
- 4 Finding enjoyment My experience is a lot of friends come and see me, support me. And you know, we play cards during dialysis as well. (F, 22-25)
 5 I feel like there's a sense in me that just wants to keep having fun. I think when getting dialysis, I couldn't have fun, I couldn't really enjoy my life as much. My
 6 participation in life was really low. So, I don't know why, but there is just an urge, I just want to keep having fun now that I can. (F, 26-30)
 7 I suppose getting a hobby, like for me, I play games and I also go to the gym. I suppose just doing things that make you feel good about yourself. (M, 22-25)
 8 I just enjoy it because I've seen the worst parts of life, now I'm enjoying the best. (M, 22-25)
- 9 Determined to do what peers can do And I think just being able to do the things that your friends do. I think that's, as a child, that was all I wanted. All I wanted was just to be in quotations "normal". And to
 10 be able to do everything that everybody else did. (F, 22-25)
 11 You want to be able to participate in the way your peers are participating, like people your age, without having to make adjustments. So, you don't feel different or left
 12 out. (F, 31-35)
- 13 Being present at social events If you are able to handle it, you should go party with your friends. Because why not? You don't have to do everything your friends are doing, you don't have to smoke
 14 or drink. (F, 18-21)
 15 I suppose just getting out there and doing things. Like if a friend invites me to go see a movie or get lunch, I just do it. (M, 22-25)
 16 I still go to a lot of activities and stuff like that. I don't let that stop me. I went on a lot of dates, met people. (F, 22-25)

Striving to reach potential and seizing opportunities

- 17 Encouragement from others My parents always made sure that my education didn't get affected because of it. I used to get hospitalized a lot, so my mother used to teach me in hospital. I used to
 18 do my homework there. (F, 22-25)
 19 I joined a Facebook group with patients from all over the world. They participated in this year's world transplant games and really encouraged us. (M, 18-21)
 20 My family, friends and faith, 3 times F, gave me the confidence to try new things, get back on my feet again, do the things I want to do. (F, 26-30)
- 21 Motivated by the illness There's a difference now where I'm no longer using it as an excuse to not do things, but as an excuse to do things. I'm making it a reason to do things. (F, 18-21)
 22 I recently started a health blog on Instagram and I'm starting a YouTube channel. (F, 22-25)
 23 I try to do my best to give them [children with CKD] advice or just try to be there for them, because I didn't have that when I was transitioning [to adult care]. I'm there
 24 for the new generation, help them cope, be that inspiration. (F, 22-25)
 25 Doing the best I can to keep fit and well. Going to the gym twice a week. (M, 22-25)
- 26 Establishing new career goals Maybe that sickness will give me strength. And it will help me if I work as a nurse. (F, 18-21)
 27 If it wasn't for hemo I wouldn't be where I am today. Like being an advocate, being working at the hospital, you know, getting that voice heard. (F, 26-30)
 28 I, for example, would not have started counselling. I wouldn't care so much about people. I wouldn't care so much about their mental health. Before kidney failure, I
 29 was into fashion. (F, 26-30)
- 30 Grateful for opportunities So I met up with him and we talked about our own experiences and now he has published a book as well. He's a big star in Taiwan, I look up to him. (F, 22-25)
 31 I'm competing in the world transplant games, I compete at the British games every year and next year I'm competing at my first European games. (M, 26-30)
 32 Got invited into lots of functions. Met lots of celebrities and sports stars. We're still friends with some of the people that are still on TV. (F, 18-21)

List of Supplementary Files**Supplementary File 1. COREQ criteria****Supplementary File 2. Ethics approval****Supplementary File 3. Interview guide**

For peer review only

Figure 1. Thematic schema



Supplementary File 1. COREQ Checklist

No.	Item	Comment	Page	Line(s)
Domain 1: Research team and reflexivity				
1	Interview/facilitator	JK	6	19
2	Credentials	JK (MD)	1	4
3	Occupation	JK, Medical Student	6	19
4	Gender	JK (Female)	6	19
5	Experience and training	Completed training in qualitative research	6	19
6	Relationship established	There were no prior relationships established	6	21
7	Participant knowledge of the interviewer	Not known to participants prior to the study	6	21
8	Interviewer characteristics	Female, medical student	6	19
Study design				
9	Theoretical framework	Qualitative study (using techniques from grounded theory)	6	27
10	Sampling	Purposive	6	12
11	Method of approach	Email/phone	6	10
12	Sample size	N=30 See table 1	7	21
13	Non-participation	Non-participation (3) was due to refusal, illness, or inability to schedule an interview after three attempts	7	23
14	Setting of data collection	A venue as preferred by the participant, or by video conference using zoom	6	20
15	Presence of non-participants	Yes, a parent was present in five interviews.	7	27
16	Description of sample	Table 1	7 (and T1)	21-26
17	Interview guide	Provided in Supplementary File 3	6 (and S3)	16-17
18	Repeat interviews	Single interview conducted	6	19
19	Audio/visual recording	Interviews were audio recorded	6	23
20	Field notes	No, not taken	6	24
21	Duration	The mean duration of the interviews was 53 minutes.	7	26-27
22	Data saturation	Yes	6	22-23
23	Transcripts returned	Yes	7	4-5
Analysis and findings				
24	Number of data coders	1 (JK)	7	1
25	Description of the coding tree	No – see themes	NR	-
26	Derivation of themes	Inductively derived from data	7	1
27	Software	HyperRESEARCH	6	27
28	Participant checking	Yes, participants were emailed a copy of the preliminary findings and invited to provide comments and we used investigator triangulation (JK, EH, CH and AT).	7	3-6
29	Quotations presented	Table 2	Table 2	-
30	Data and findings consistent	Quotations provided to illustrate each theme.	8 - 14	16 - 14
31	Clarity of major themes	Yes – themes	8	4-6
32	Clarity of minor themes	Yes – see subthemes and description of the themes	8	4-6

Supplementary File 2. Ethics approval

Ethics Committee(s) and/or Institutional Board(s) that approved this study (+ number/ID):

- The University of Sydney, Sydney, NSW, Australia (2017304)
- The Sydney Children's Hospital Network, Western Sydney Local Health District, Sydney, NSW, Australia (8718)
- Royal Children's Hospital, Monash Health, Melbourne, VIC, Australia (13082B)
- Princess Alexandra Hospital, Metro South Health, Brisbane, QLD, Australia (17QPAH/112)

For peer review only

Supplementary File 3. SONG-Kids Interview guide

Introduction

1. Could you briefly tell me about your experience growing up with kidney problems/kidney disease?
2. How does CKD impact on your life at the moment? How is it different now, compared to when you were a child living with kidney disease? What are things you missed out on?

Meaning of life participation

3. Life participation, or being able participate in life, has been found to be an important thing to focus on in research in children with CKD. Caregivers, young patients and health care providers told us this was important.
 - What do you think of when I say "life participation," what does it mean to you?
 - How would you define 'life participation'?
4. Life participation is about being able to do the things that are meaningful and important to you. What things/activities are important to you or other young adults with kidney disease - Why? (work/career, income, family/having children, education, travel, intimate relationships, social life, physical activity, freedom/flexibility, independence)
5. Do you think the meaning (or the types of activities) of life participation is different between young adults with kidney disease, and young adults without kidney disease – why?

Experience of life participation during childhood

6. As a child, what areas of your life were most impacted or limited? (school, travel, social life, quality of life, physical activity, freedom and flexibility)
7. Has your ability to participate in life changed over time, throughout your journey with CKD? How?

Impact of (childhood) CKD on life participation in young adulthood

8. Has your ability to participate in life been shaped (or impacted) by having childhood CKD? How?
9. What areas of your life have been most impacted or limited? How/Why? (work/career, income, family/having children, education, travel, intimate relationships, social life, physical activity, freedom and flexibility, independence)
10. What about your future? Are there areas of your life that you believe will be impacted or limited due to CKD?

Improving life participation

11. Do you think life participation should be discussed/or addressed by health care providers – why/how?
12. Has anything helped to improve your ability to participate in life - how? What about when you were a child?
13. Can you suggest things that may be helpful to improve life participation for young adults? What about for children with kidney disease?

Supplementary File 1. COREQ Checklist

No.	Item	Comment	Page	Line(s)
Domain 1: Research team and reflexivity				
1	Interview/facilitator	JK	6	19
2	Credentials	JK (MD)	1	4
3	Occupation	JK, Medical Student	6	19
4	Gender	JK (Female)	6	19
5	Experience and training	Completed training in qualitative research	6	19
6	Relationship established	There were no prior relationships established	6	21
7	Participant knowledge of the interviewer	Not known to participants prior to the study	6	21
8	Interviewer characteristics	Female, medical student	6	19
Study design				
9	Theoretical framework	Qualitative study (using techniques from grounded theory)	6	27
10	Sampling	Purposive	6	12
11	Method of approach	Email/phone	6	10
12	Sample size	N=30 See table 1	7	21
13	Non-participation	Non-participation (3) was due to refusal, illness, or inability to schedule an interview after three attempts	7	23
14	Setting of data collection	A venue as preferred by the participant, or by video conference using zoom	6	20
15	Presence of non-participants	Yes, a parent was present in five interviews.	7	27
16	Description of sample	Table 1	7 (and T1)	21-26
17	Interview guide	Provided in Supplementary File 3	6 (and S3)	16-17
18	Repeat interviews	Single interview conducted	6	19
19	Audio/visual recording	Interviews were audio recorded	6	23
20	Field notes	No, not taken	6	24
21	Duration	The mean duration of the interviews was 53 minutes.	7	26-27
22	Data saturation	Yes	6	22-23
23	Transcripts returned	Yes	7	4-5
Analysis and findings				
24	Number of data coders	1 (JK)	7	1
25	Description of the coding tree	No – see themes	NR	-
26	Derivation of themes	Inductively derived from data	7	1
27	Software	HyperRESEARCH	6	27
28	Participant checking	Yes, participants were emailed a copy of the preliminary findings and invited to provide comments and we used investigator triangulation (JK, EH, CH and AT).	7	3-6
29	Quotations presented	Table 2	Table 2	-
30	Data and findings consistent	Quotations provided to illustrate each theme.	8 - 14	16 - 14
31	Clarity of major themes	Yes – themes	8	4-6
32	Clarity of minor themes	Yes – see subthemes and description of the themes	8	4-6

Standards for Reporting Qualitative Research (SRQR)*

<http://www.equator-network.org/reporting-guidelines/srqr/>

Page/line no(s).

Title and abstract

<p>Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended</p>	1/ 2
<p>Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions</p>	3/ 1-24

Introduction

<p>Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement</p>	5/ 3-8 5/ 10-19
<p>Purpose or research question - Purpose of the study and specific objectives or questions</p>	5/ 21-25

Methods

<p>Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**</p>	7/ 1-6
<p>Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability</p>	6/ 18-21
<p>Context - Setting/site and salient contextual factors; rationale**</p>	6/ 20-21
<p>Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**</p>	6/12-13 and 6/ 21-23
<p>Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues</p>	18 / 11-19
<p>Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**</p>	6 / 18 and 7 / 3-4

1 2 3 4 5	Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	6/ 16-17 and 6/ 23
6 7 8	Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	7/ 20-27 and Table 1
9 10 11 12	Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	6/ 23-27 and 7 / 1-2 and Table 2
13 14 15 16	Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	6/27 and 7/ 1-6
17 18 19 20	Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	7/ 3-4 and 16/ 2

Results/findings

23 24 25 26	Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	8/ 3-13
27 28 29	Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Table 2

Discussion

32 33 34 35 36 37	Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	14/ 18-26 and 15/ 16-25 and
38 39	Limitations - Trustworthiness and limitations of findings	16/ 3-9

Other

42 43 44	Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	4 / 17
45 46	Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	4/ 12-14

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014
DOI: 10.1097/ACM.0000000000000388

For peer review only