

## PEER REVIEW HISTORY

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### ARTICLE DETAILS

<b>TITLE (PROVISIONAL)</b>	Perspectives on life participation by young adults with chronic kidney disease: an interview study
<b>AUTHORS</b>	Kerklaan, Jasmijn; Hannan, Elyssa; Hanson, Camilla; Guha, Chandana; Cho, Yeoungjee; Christian, Martin; Hamiwka, Lorraine; Ryan, Jessica; Sinha, Aditi; Wong, Germaine; Craig, Jonathan; Groothoff, Jaap; Tong, Allison

### VERSION 1 – REVIEW

<b>REVIEWER</b>	Kristof Thys KU Leuven, Belgium
<b>REVIEW RETURNED</b>	15-Apr-2020

<b>GENERAL COMMENTS</b>	<p>This manuscript reports the findings of a qualitative study investigating the perspectives on life participation by young adults with childhood-onset chronic disease. Based on a thematic analysis of thirty semi-structured interviews, the authors identified several constraints to successful life participation, including struggles with day-to-day restrictions in several activities, complaints of delayed independence and lack of social skills, as well as feelings of defeat and hopelessness about the future. These constraints challenged patients to maintain focused on the present and to reorient long-term goals. For some patients, engaging in normal activities and pursuing new goals and opportunities impacted life participation positively. The authors recommend further research on validated patient-reported outcome measures for life participation in this patient group.</p> <p>The research manuscript looks promising and addresses an important though understudied area. Important strengths of the manuscript include the broad range of (demographic and clinical) participant characteristics, the international context of the study, the use of investigator triangulation and member checking to improve the accuracy of data analysis, the in-depth and clear description of the research results, the inclusion of illustrative quotes, as well as appropriate consideration of the study limitations.</p> <p>Here are some points that the authors might consider in order to improve their manuscript:</p> <p>* I feel the authors can strengthen the introduction by elaborating more in detail on the study rationale. More specifically, it would be interesting for the reader to know why 'life participation' should be considered as a separate concept and how it is different from (and relates to) other outcomes, such as quality of life.</p>
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	<p>* I believe the results section could be improved by adding an introductory paragraph that discusses the relationship between the core themes, as presented in figure 1 (rather than merely summing up the different themes). This would clarify the overall storyline for the reader.</p> <p>*In the thematic schema (figure 1), reorienting plans and goals is marked as having a neutral impact on life participation. This may need some explanation, as some of the quotes suggest for instance that some participants (at least initially) struggled with issues such as the possibility of birth defects, health risks due to pregnancy and making other adjustments to their lives. Do the authors mean that participants were, in the end, able to overcome such struggles so that they did not impact their participation to valued activities markedly positively or negatively? Or was the impact of this reorientation process very different from one person to another?</p> <p>Thank you for the opportunity to review this interesting manuscript.</p>
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### VERSION 1 – AUTHOR RESPONSE

#### Reviewer comments:

1. I feel the authors can strengthen the introduction by elaborating more in detail on the study rationale. More specifically, it would be interesting for the reader to know why 'life participation' should be considered as a separate concept and how it is different from (and relates to) other outcomes, such as quality of life.

We have provided the rationale for the focus on life participation as this was a critically important outcome as identified through the SONG-Kids initiative. As suggested, we expanded the introduction to clarify the difference between life participation and quality of life: "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 concerns." (4). 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 hope (5). For children with CKD, meaningful activities include study, sport, social and leisure activities (2,3) (Page 5, paragraph 2 – marked copy)

2. I believe the results section could be improved by adding an introductory paragraph that discusses the relationship between the core themes, as presented in figure 1 (rather than merely summing up the different themes). This would clarify the overall storyline for the reader.

We have added a paragraph to demonstrate the links among the themes. Please see our response to Point #8 below.

3. In the thematic schema (figure 1), reorienting plans and goals is marked as having a neutral impact on life participation. This may need some explanation, as some of the quotes suggest for instance that some participants (at least initially) struggled with issues such as the possibility of birth defects, health risks due to pregnancy and making other adjustments to their lives. Do the authors mean that participants were, in the end, able to overcome such struggles so that they did not impact their participation to valued activities markedly positively or negatively? Or was the impact of this reorientation process very different from one person to another?

As suggested we have added an introductory paragraph to discuss the relationships among the themes with reference to Figure 1. "Young adults who grew up with CKD struggled with daily restrictions, felt defeated and hopeless, and lagging behind in their studies and other life goals. They had to give up valued activities, lacked confidence and social skills, were uncertain of the future, and felt vulnerable. Some had to reorient their plans and goals. Some participants initially

struggled with this then overcame these struggles and re-adjusted their goals. They immersed themselves in “normal” activities, refusing to miss out and were determined to do what their peers could do. Some strived to reach potential and seize opportunities. (Figure 1)” - (Page 8, paragraph 2 – marked copy).

Again, we appreciate the editorial and review comments that have helped to improve and strengthen the manuscript. Thank you in advance for reviewing our revised manuscript and we look forward to hearing from you.

Kindest regards  
Jasmijn Kerklaan on behalf of all authors

References

1. 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.
2. 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. *American Journal of Kidney Diseases* (2020).
3. 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 International* (2020).
4. World Health Organization available at <https://www.who.int/healthinfo/survey/whoqol-qualityoflife/en/>. Accessed 23th of July 2020.
5. Ju A, Josephson, M. A., Butt, Z et al. Establishing a core outcome measure for life participation: A standardized outcomes in nephrology-kidney transplantation consensus workshop report. *Transplantation* 103.6 (2019): 1199-12 05.

**VERSION 2 – REVIEW**

<b>REVIEWER</b>	Kristof Thys KU Leuven, Belgium
<b>REVIEW RETURNED</b>	27-Aug-2020
<b>GENERAL COMMENTS</b>	Thank you for the revisions. I believe the authors have provided a stronger rationale for the study by explaining the difference between life participation and quality of life. I have no additional comments.