

**Supplementary Table 1. Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist**

No Item Guide questions/description

*Domain 1: Research team and reflexivity*

*Personal Characteristics*

**1. Interviewer/facilitator**

**Which author/s conducted the interview or focus group?**

Workshops were conducted by Simón M. Lanza Rodelgo (Workshop 1) and Catalina Peña Guerra (Workshop 2).

**Who were the interviewers?**

The same authors.

**2. Credentials**

**What were the researcher's credentials?**

Simón and Catalina are health anthropologists

**3. Occupation**

**What was their occupation at the time of the study?**

Researchers

**4. Gender**

**Was the researcher male or female?**

One was male and the other female.

**5. Experience and training**

**What experience or training did the researcher have?**

The interviewers received specific training in Nephropathic cystinosis.

*Relationship with participants*

**6. Relationship established**

**Was a relationship established prior to study commencement?**

None

**7. Participant knowledge of the interviewer**

**What did the participants know about the researcher? e.g. personal goals, reasons for doing the research**

The participants did not know the researcher

**8. Interviewer characteristics**

**What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic**

None.

## *Domain 2: study design*

### Theoretical framework

#### **9. Methodological orientation and Theory**

**What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis**

Participant selection

#### **10. Sampling**

**How were participants selected?** e.g. purposive, convenience, consecutive, snowball

“Participant recruitment was achieved through the patient Spanish Cystinosis Association Grupo Cistinosis”.

But how were they selected and approached?

The association asked patients and caregivers if they like to participate.

#### **11. Method of approach**

**How were participants approached?**

By phone and email.

#### **12. Sample size**

**How many participants were in the study?**

6 patients in the interviews, 4 patients and 4 caregivers in the workshops.

#### **13. Non-participation**

**How many people refused to participate or dropped out? Reasons?**

No

Setting

#### **14. Setting of data collection**

**Where was the data collected?** e.g. home, clinic, workplace

Interviews and workshops were online

#### **15. Presence of non-participants**

**Was anyone else present besides the participants and researchers?**

Parents of pediatric patients. Anyone else? No

#### **16. Description of sample**

**What are the important characteristics of the sample?**

The opinions and experiences of both patients and caregivers on how they have experienced the disease, what problems they have encountered during the patient journey and adherence to treatment

#### **Data collection**

##### **17. Interview guide**

**Were questions, prompts, guides provided by the authors? Was it pilot tested?**

Yes, a questionnaire was developed. No pilot test was performed.

##### **18. Repeat interviews**

**Were repeat interviews carried out? If yes, how many?**

No

**19. Audio/visual recording**

**Did the research use audio or visual recording to collect the data?**

The researchers used a Miro online whiteboard.

20. Field notes

Were field notes made during and/or after the interview or focus group? Yes

21. Duration

What was the duration of the interviews or focus group?

Interviews, 40-60 minutes. Workshops, 2 hours.

22. Data saturation

Was data saturation discussed? Yes, data saturation appeared and was discussed

23. Transcripts returned

Were transcripts returned to participants for comment and/or correction? No

*Domain 3: analysis and findings*

Data analysis

24. Number of data coders

How many data coders coded the data?

Two data coders were involved in coding the data independently to ensure inter-coder reliability

25. Description of the coding tree

Did authors provide a description of the coding tree?

The authors provided a detailed description of the coding tree, including definitions for each code, the hierarchical structure of themes, and illustrative examples from the data.

26. Derivation of themes

Were themes identified in advance or derived from the data?

Themes were primarily derived inductively from the data through an iterative process of open and axial coding. However, some codes were based on pre-existing literature, representing a combination of inductive and deductive approaches

27. Software

What software, if applicable, was used to manage the data?

Atlas TI

28. Participant checking

Did participants provide feedback on the findings?

No

Reporting

29. Quotations presented

Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number

No

30. Data and findings consistent

Was there consistency between the data presented and the findings?

Yes

31. Clarity of major themes

Were major themes clearly presented in the findings?

Yes

32. Clarity of minor themes

Is there a description of diverse cases or discussion of minor themes?

NO