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| **Table S1: COREQ (COnsolidated criteria for REporting Qualitative research) Checklist**  A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A | | | |
| **Topic** | **Item No.** | **Guide Questions/Description** | **Reported on**  **Page No.** |
| **Domain 1: Research team and reﬂexivity** | | | |
| *Personal characteristics* | | | |
| Interviewer/facilitator | 1 | Which author/s conducted the interview or focus group? | pp.6, 7 |
| Credentials | 2 | What were the researcher’s credentials? E.g. PhD, MD | p.7 |
| Occupation | 3 | What was their occupation at the time of the study? | p.7 |
| Gender | 4 | Was the researcher male or female? | p.7 |
| Experience and training | 5 | What experience or training did the researcher have? | pp. 7,25 |
| *Relationship with participants* | | | |
| Relationship established | 6 | Was a relationship established prior to study commencement? | p.7 |
| Participant knowledge of  the interviewer | 7 | What did the participants know about the researcher? e.g. personal  goals, reasons for doing the research | p.6 |
| Interviewer characteristics | 8 | What characteristics were reported about the inter viewer/facilitator?  e.g. Bias, assumptions, reasons and interests in the research topic | NR |
| **Domain 2: Study design** | | | |
| *Theoretical framework* | | | |
| Methodological orientation and Theory | 9 | What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology,  content analysis | pp. 5,7 |
| *Participant selection* | | | |
| Sampling | 10 | How were participants selected? e.g. purposive, convenience,  consecutive, snowball | p.5 |
| Method of approach | 11 | How were participants approached? e.g. face-to-face, telephone, mail,  email | p.6 |
| Sample size | 12 | How many participants were in the study? | p.6 |
| Non-participation | 13 | How many people refused to participate or dropped out? Reasons? | pp.6,25 |
| *Setting* | | | |
| Setting of data collection | 14 | Where was the data collected? e.g. home, clinic, workplace | p.7 |
| Presence of non-  participants | 15 | Was anyone else present besides the participants and researchers? | p.7 |
| Description of sample | 16 | What are the important characteristics of the sample? e.g. demographic  data, date | p.6, Table 1 |
| *Data collection* | | | |
| Interview guide | 17 | Were questions, prompts, guides provided by the authors? Was it pilot  tested? | p.6 |
| Repeat interviews | 18 | Were repeat interviews carried out? If yes, how many? | No |
| Audio/visual recording | 19 | Did the research use audio or visual recording to collect the data? | p.7 |
| Field notes | 20 | Were ﬁeld notes made during and/or after the interview or focus group? | NR |
| Duration | 21 | What was the duration of the inter views or focus group? | p.7 |
| Data saturation | 22 | Was data saturation discussed? | p.25 |
| Transcripts returned | 23 | Were transcripts returned to participants for comment and/or correction? | No |

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| **Domain 3: analysis and ﬁndings** | | | |
| *Data analysis* | | | |
| Number of data coders | 24 | How many data coders coded the data? | p.7 |
| Description of the coding  tree | 25 | Did authors provide a description of the coding tree? | p. 8, Suppl.File 2 |
| Derivation of themes | 26 | Were themes identiﬁed in advance or derived from the data? | p.7 |
| Software | 27 | What software, if applicable, was used to manage the data? | NA |
| Participant checking | 28 | Did participants provide feedback on the ﬁndings? | No |
| *Reporting* | | | |
| Quotations presented | 29 | Were participant quotations presented to illustrate the themes/ﬁndings?  Was each quotation identiﬁed? e.g. participant number | Yes |
| Yes, mother, father and a number |
| Data and ﬁndings consistent | 30 | Was there consistency between the data presented and the ﬁndings? | Yes  In the Result section, specific quotes from mothers and fathers’ interviews are used to support the findings and provide consistency between the data and the findings. See also question 31. |
| Clarity of major themes | 31 | Were major themes clearly presented in the ﬁndings? | Yes, pp. 8-20, Table 2  In the first paragraph of the Result section the overarching theme is stated, and it is described how it is represented in the data. Also, how it emerged. In Table 2 shows this as well. |
| Clarity of minor themes | 32 | Is there a description of diverse cases or discussion of minor themes? | Yes, pp.8-20  The 4 categories and 15 subcategories are described in Table 2. By the use of specific headings, it is clear what category and subcategories are being described. The subcategories are explained in details, and there is a description of diverse cases, including parent of a child that died, parent of a child that had complications after heart surgery, and parents needing to travel three times abroad. |