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| **Guideline for interviews with parents.** |
| **Questions regarding the child** |
| * Please try to briefly describe the palliative care your child receives. * How is your child doing now?   + How does the palliative care figure into the improvement/deterioration of your child? * Can the palliative care support your child somehow?   + How exactly?   + How do you notice it is effective?   + Have any changes occurred for your child as a consequence of the palliative care? If yes, what changed? * What does everyday life look like for your child these days?   + Have any changes occurred in your child’s daily routine since palliative care started?   + In how far has the palliative care affected these changes? * Is there any aspect that prevails for you regarding the palliative care of your child? If yes, have any changes occurred regarding this aspect that are due to the palliative care? * What effect did the care have on your child? Please try to describe the most important changes regarding your child that have occurred as a consequence of receiving palliative care. |
| Questions regarding the parents |
| * How do you experience receiving palliative care for your child and your family?   + Do you feel like you benefit personally from receiving care? Can you explain how?   + How are you being supported by palliative care services?   + Have any important changes occurred for you personally as a consequence of the palliative care? * Which offers provided through the palliative care are you making use of?   + How would you rate these offers?   + Do you miss any specific offers? * You have already told me about your child’s daily routine. What does your own daily routing look like?   + Have any changes in your daily routine resulted from receiving palliative care?   + What meaning do these changes bear to you? * What does your social life look like recently?   + Have any changes in your social life occurred as a result of receiving palliative care? * What meaning does the care you receive have for you? |
| **Questions regarding other family members (e.g. siblings, grandparents)** |
| * Describe how the palliative care team interacts with your child’s siblings   + Do the siblings take part in any activities/offers provided by the palliative care team?   + How would you rate the activities/offers for siblings? * How do the siblings cope with the palliative care?   + Have any changes for the siblings occurred as a result of the palliative care? * What about other involved family members (e.g. grandparents)?   + In how far does the palliative care include/address them?   + How would you describe the palliative care team’s interaction with the other family members?   + Have any changes occurred for the other family members as a consequence of the palliative care? |
| Questions regarding the involved staff |
| * What is your impression of the palliative care team’s physicians/therapists/nurses etc.?   + What does the collaboration with the palliative care team look like?   + What goes well?   + Is there anything that you desired from the palliative care team that has not happened/has not been done?   + Have there been situations in which you were unsatisfied with the palliative care team? Please describe those situations. |
| **Summary** |
| * In summary, what are the positive aspects of being cared for by a palliative care team? * What are negative aspects that result from being cared for by a palliative care team? What are potential shortcomings of the care? * Lastly, do you have any suggestions for improvement for the palliative care teams? |
| *Note.* First-order bullet points represent the main questions. Second-order bullet points represent optional follow-up questions. |