Conversation guide for professionals:

conversation with parents

Impact

Talking together about care & treatment

Step 1: Introduction

1.1 Make the goal of the conversation clear

Today we are going to talk about what you think is important for the care of [child's name] and about your perspectives regarding your child's and family's future. By talking about these issues in time, we aim to align the care provided to [child's name] with your preferences and goals.

Step 2: Exploration

To get to know you better, I would like to get a better idea about how you think about all sorts of things. To help me to do this, I would like to ask you a series of questions. Is this alright with you?

2.1 Exploring **identity**

As a parent, how would you describe [child's name]? What do you think is important in [child's name]'s life?

2.2 Exploring **illness experience**

What does [child's name]'s disease or condition mean to you as parents? What does it mean for you as a family? How do you think your child's disease or condition will evolve? What does this mean for [child's name] and your family? Did you hear from any experiences of other parents or families? What do these experiences mean to you?

2.3 Exploring **quality of life**

How does a good day for [child's name] looks like? What do you consider important for [child's name] quality of life? Is there anything you do want to achieve for [child's name]?

2.4 Exploring **expectations for the future**

How do you think [child's name]'s future will look like? What are your expectations for [child's name]'s future? What does this mean to your child and to you as parents and family? Do you have any goals for your child? When you think about the future, what do you hope for? And what else do you hope for? And if that doesn't work out, what else would you hope for? What does [child's name] hope for?

2.5 Exploring **the role of the parents**

What sort of a parent are you to [child's name]? What sort of a parent would you like to be to [child's name]? Where do you get strength and support from? Do you have a particular believe system? What makes you feel supported in your life? How is this for your child? Where does [child's name] get his/her strength from?

Step 2: Exploration

2.6 Exploring views on life

What fears and worries does [child's name] have? What concerns do you have about [child's name]'s future? And what about yourselves/yourself? Where are you afraid of? With are your fears and worries?

2.7 Exploring fears and worries about the future

From my experience as a doctor for children with [name of disease], I know that [state expectation for future] could play a role. As parents, what are your thoughts about this?

2.8 Further information about expectations for the future (if necessary)

What does [child's name] think is important for his/her care and treatment? In your opinion, as parents, what is the goal of the care and treatment of [child's name]? Is there anything you do not want for [child's name]?

2.9 Exploring of goals and preferences for care

We hope it won't happen, but just say things started to get slowly worse with [child's name], what would you hope for? What would you consider important if [child's name] became slowly more ill? What would you consider important if [child's name] became acutely ill? What do you think about invasive treatments, such as resuscitation and ventilatory support? What would you consider to be important if we thought that your child did not have long to live? What would you hope for in that case? Where do you think [child's name] would like to be in case his/her end of life approaches?

2.10 Exploring goals and preferences for care at differing stages of illness (if necessary)

From what you are saying, I can hear that you think [summarize desired care goals] is/are important for [naam kind]. And that is why I think that the doctors and nurses should aim to [goals of care]. That means that [explain care]. What do you think about it?

2.11 Summary of exploration

Uit wat u zegt, hoor ik dat u het belangrijk vindt dat… Daarom denk ik dat we ons moeten richten op…Dat betekent…
Hoe kijkt u daar tegenaan?

Step 3: Decision-making

From what you have just told me, I now know better what you think is important to [child's name] and you as a family. We have now come to the part of the conversation, where we look at the sort of medical goals that fit your goals and preferences. If necessary, we can also make the decisions about [child's name]'s care and treatment. In any case, we can make an agreement about what the main goals of your care and treatment should be.

3.1 Designate decision-making roles

As parents, what is your role in making decisions about the care and treatment of [child's name]? Is there anyone else involved in making decisions regarding [child's name] 's health? How is [child's name]'s perspective taken into account?

3.2 Further information about goals of care (if necessary)

I know that other children with the same disease or their parents thought it was important that…I would like to explain to you why I think that it would be good if we thought about…Is that alright with you?

3.3 Establish care goals

What do you think are the main goals of care regarding [child's name]'s care and treatment? Do you have any other goals for [child's name]? What is needed to achieve those goals? What steps do you think should be taken?

3.4 Documenting

What would you like to write in [child's name]'s medical record? What sort of things should other people know? And who should know?

Step 4: Rounding off

4.1 Summarize the conversation

Shall I sum up what we have talked about up to now? [child's name] is a person who [summarize identity]. What you as parents think about [child's name]'s life is [summary of attitude to life]. What the disease means to you is [summary of disease experience]. If we think about the future of [child's name], we expect that [summary of expectations for the future]. The things that you think are important about [child's name]'s care and treatment are [summary of goals of care]. If the condition of [child's name] deteriorates, you think it is important [summary of care preferences]. Your goals of care are [summary of goals of care]. Together, we are going to work towards [summary of decision-making process]. Have I gotten it right?

4.2 Enquire about other subjects

To the parents: Is there anything else you would like to discuss?

4.3 Plan a follow-up conversation

Because [child's name]'s situation may change over time, I think it is a good idea if we talk like this again. Is that alright with you? When would you like to talk about this again?

Notes

Colofon:

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Implementing Pediatric Advance Care Planning Toolkit

IMPACT is the result of a collaboration between the UMC Utrecht, the Erasmus MC and the Knowledge Center for Child Palliative Care; it was developed with the cooperation of children, parents, and professionals working in childcare and children's hospitals.

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