

Interview guide

A translated version (from Dutch to English) of the interview guide on which the semi-structured interviews were based.

- By whom and how were you informed about X's condition (X = the patient)?
- Can you tell us what your first reaction was when you learned the news about X?
- Did you immediately see a task for yourself in the support of X's partner Y?
 - o How did you fill that role?
 - o Were others involved?
 - o Can you tell me more about this?
- Did you talk to anyone about supporting Y outside the so-called team?
 - o Have you sought advice from anyone?
 - o Did anyone give you unsolicited advice?
 - o In what ways did you find out what is expected of you and how you should act upon that?
- How would you describe the support of Y?
- Has anything changed in your relationship with Y since the diagnosis?
 - o How would you describe this?
 - o What triggered this change?
- Do you have contact with other family members/friends/caregivers of X or Y? We will refer to this group as the team from now on.
 - o Did you also know these people before the diagnosis?
 - o Has anything changed in your relationship with Y? What has changed?
- Can you give a brief overview of who is on the team? Who is involved in caring for Y or X and what is each person's role?
- Can you describe how communication within the team works?
 - o Who takes the initiative?
 - o What is and is not communicated?
 - o With whom do you communicate and with whom do you not?
- When do you struggle with this care? When does it feel more like a task?
 - o Can you clarify this with an example?

Additional file 3

- How do you deal with this?
- When do you feel like everything is working out?
 - Can you provide an anecdote of this?
- Looking at the whole network or team around Y, how would you situate yourself in this? How do you yourself function within this group?
- If you could dismiss one person from the group, who would it be and why?
- If you were allowed to choose one person who should definitely stay in the group, who would this be and why?
- What makes you continue to provide this care?
- Under what circumstances would you stop providing care?