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| **BREATHER carer topic guide** | | | |
| **Key area of investigation** | *Rationale* | **Themes** | **Example questions**  These are not to be followed as a script. Not all questions needs to be asked. They are ideas for questions. |
| **It is important in your introduction that you make it very clear that although you have spoken with their child that each individual is confidential. Therefore just as you will not be revealing anything about what the child has told you, you will not tell the child (or anybody else) anything that is mentioned in today’s interview. So they should feel free to talk to you about whatever they want with confidence that it will not be shared with child X.** | | | |
| **Tell me about yourself** | *It may not be necessary for this section to take very long, but the function of this stage is to encourage the participant to talk about themselves, for the interviewer to demonstrate interest in them individually and to provide some context to further conversations. This section is to help them warm up!*  You may want to be prepared to find ways to respond to participants telling you straight away about people who may have passed away, being widowed, have lost their own children and so on.  **Throughout the interview you will need to adjust ALL your questions to the individual in front of you.**  *This stage is intended to:*  *Demonstrate interest in their lives.*  *Encourage participants to start talking relatively freely.* | * Explore background circumstances      * Household (who they live with), exploring family relationships. * Marital status and relationship status. * Occupation and education. * Sources of income and support | * So I can know a bit more about your day to day life, can you tell me a bit about yourself? |
| **Caring responsibilities and activities**  **(overall experience) within the household** | *This section is to find out who they are caring for, what they do for them and how they find it.*  *This includes talking about everyone in the household.*  *This may involve them talking in specifics about the young person involved in the study. If it doesn’t this should be pursued in the next section of the interview if appropriate.*  *This includes talking about those who may not be biological kin.*  Although we will ask them later, participants might mention here the circumstances of HIV in the household (e.g. whether they are living with it, others who may be living with it, be ill, or have died etc.)**You may need to pay attention to this as it will help to set up further question you can return to later in the interview.** This may play a role in shaping how carers talk to the children about HIV (or not), and the ways in which they see the future etc. as we discussed in the memo**.** | * Caring responsibilities (who and why they are looking after them) * Caring practices (what they do for them) * Experiences of caring for them * Additional support they get in caring for them (anyone help, who, how) * Attitudes towards caring for them | * So you have mentioned a number of people that you live with. Who do you look after? * How did you come to look after y and z? * Does anyone else help you in caring for x/ these children? |
| **Caring for child in the study** | *Caring for specific child.*  *This may include discussion of the child’s illness history/ history of parents (if child not their own offspring).*  *Exploring how this care differs from the care given to others in the household.*  *Attitudes of others to child in the household.*  *Exploring the HIV status of others within the household*  *Probing for differences in caring for child who is HIV (if known) than others in the household* | * Specific care given to X? Including clinic attendance, nursing, treatment support, cooking and feeding. * Illness history (and HIV diagnosis and disclosure if they are aware of this) * Status of others within the household. * Child’s abilities (educational, physical) | * What care do you give X? * Does this differ in any way from the care that you give the others? How? Why? * Does anyone else take HIV treatment in the household? * Does X know about this? * How do the others take their treatment? Tell me about how it works? * Do you think that their illness/ HIV has affected their abilities/ capacity in any way? (try not to suggest things here, as this would be leading, but what we mean are things like school work/ achievements)? |
| **Adherence, support and challenges** | *Exploring carers’ understanding of what is ‘good adherence’’*  *Exploring the ‘exemplary adherer’ story as pre-condition for the trial*  *Exploring possible difference in adherence accounts of children and carers* | * Treatment support – what it looks like (if this has not come up yet) * Challenges to treatment support (e.g. do/can they know whether child takes treatment; side-effects; other obstacles) * Conversations about treatment (does the child ask questions?) | * Who has primary responsibility for the child remembering to take treatment? How does that work? * Has it always been like this? * When did this change? How did you feel when it changed? * How do you feel about it now? * ***(If applicable)*** Do you take treatment together (always/sometimes)? * Do you think people would blame you for any adherence problems X might have? * What would help/support in those circumstances? * Has X ever talked to you about any problems with taking treatment? |
| **Taking part in the BREATHER trial** | *Understanding how decision to participate was made (and by whom)*  *Exploring potential hopes and anxieties of carers*  *Understanding experience of SCT from carers’ perspective (of children on SCT arm)*  *Exploring trial experience from carers’ perspective* | * Understanding of what the trial is for * Informed consent issues (of carer and/or of child) * Early phase of the trial * Starting SCT (for those on SCT arm) * SCT over time from both perspective * Being in the trial over all | * Can you tell me a little bit about your views on the BREATHER trial? * Can you tell me about when you agreed that X could take part? * And about when X agreed or assented to take part? * Did you ever consider not taking part? Why? * Did X agree? * Can you tell me a bit about your discussions with X about the trial? * What were your thoughts when X started taking part in the trial? * Which arm was X randomised into? * How where things when X started in the trial?   ***For those whose children are on SCT arm***   * Do you think SCT made any difference to X? In what way? * Has SCT meant any difference for you in caring for X?   ***For everyone***   * What *(If anything)* did you think was good about X being in the trial? And what was not so good? * Would you consider X taking part in other trials in the future? * Do you think SCT could be an option for X in the future? Why? |
| **Disclosure of child’s status to the child** | *We know that it is common for there to be little further talk about HIV post disclosure, despite many children wanting to. This is an opportunity to explore how this is considered by carers.*  You can consider introducing this section by asking whether discussions about being part in the trial have led to discussions about HIV. Then you could say that some of the children in this and other studies told us there was not much talk about HIV in the house – and move on to the themes/questions. | * Disclosure experience- including what is covered * Decision leading to disclosure (including reasons for any delays/ postponing of disclosure) * Talk post disclosure * Learning from disclosure experience * Carers’ view of whether is better for children not to think or talk about HIV | * Who disclosed to X? Can you tell me about how that came about and what? * What were they told? * Why was it done at that time? * Had you thought about doing it before this? * What were you expectations of what it would be like to tell x? * What was it like for you during this time? * Have you discussed it since? Would you like to? * Do they know how they became infected? How do you know? * Do you think that X has any questions or things that they would like to discuss with you? * Has the disclosure of their status had any effect on them? On your relationships? Did you have any concerns that it might/ Why? |
| **Carers’ own experience of disclosure** | *Here we want to explore whether carers approach to keeping HIV ‘secret’ may be the result of their own past experiences with disclosure.*  *We can do this* ***only for those participants who have already talked about their own status during the interview.*** *We would not bring it up otherwise.* | * Exploring extent of disclosure * Exploring prior disclosure experiences (and perceptions of change over time) * Exploring carers’ thinking in relation to the child disclosing | * Have you told anyone about your status, aside from the people here in the clinic? * Have you told X? ***(Do not ask if mentioned already in the interview)*** * How have the people you told reacted to your status? * How did you feel at that time? Do you feel the same now? * Do you think there are risks or benefits involved in ~~X~~ talking to others about one’s status? * Do you think these risks/benefits are the same for X? How do they differ? How are they the same? |
| **Impact of SCT on child’s disclosure to others; isolation issues; and disclosure going forward** | *We are also interested in the impact of SCT on*  *disclosure for children on SCT – do carers see SCT as helpful to keep HIV disclosure/talk to a minimum? [They may have mentioned this as part of the hopes when child started SCT, you can perhaps expand here.]*  *We are also interested in seeing whether carers understand the levels of isolation many of the children talk about. They may think SCT has helped children to make friends.*  *We need to also find out whether carers think peer groups would help.* | * Impact of SCT on disclosure * Views of carers on future disclosures * Views on risks benefits (to them or to the child) of disclosure of child status * Peer support issues | * Do you think SCT has changed how X manages his status? *(or please find a better way of saying this!)* * If X can continue on SCT, do you think this will be helpful? How? * Do you think there will be a time when X will be able to talk more openly about his/her status? * Do you think X might like to meet other children living with HIV? Would you like that? |
| **Growing up with HIV** |  | * Specific risks for those living with HIV * Impact of HIV on the future of their child/ young people in general * Perceived differences I outcomes and expectations across transmission routes, in general and for their futures | * Does X’s HIV status influence your concern for them? * In interviewing X we talked about their dreams for the future. Do you think that their HIV status will have any impact on their future? How? Why? How do you feel about that? * Do you think that it influences how they imagine their future? * Have you ever talked about this? Why/ not? * Do you think it makes any difference to a young person how they became infected? Why? |
| **Closing the interview- needs of carers** | *In closing the interview focus on what may help carers meet the needs of young people that they are looking after.*  *This section is to help the conversation finish on a more proactive note.*  **Reinforce the confidentiality of the interviews and that as nothing that the child has said has been disclosed to them, similarly nothing that they have said will be discussed with their child.**  **Thank them for their time.** | * Final views on SCT Support available to carers * Support needs of carers- specifically for them and more generally, including information and peer support. | * What are your final views on the idea of young people having the weekend off treatment (as in SCT)? * Do you think SCT is a safe option? * Finally, we have spoken about the challenges in caring for X, what do you think would help you and other carers like you? |