

Supplemental Online Table 1. Survivorship-related interview questions

<p>1. How are you and your survivor are doing right now?</p> <p>Follow-up prompts: What was treatment like for you, your family, and child? What was it like to end treatment? How well do you think the doctors and healthcare team did a good job transitioning you and your child into survivorship?</p>
<p>2. Can you recall being counseled on survivorship (late effects, follow-up care, long-term risks, continuing challenges) by your healthcare team?</p> <p>Follow-up prompts: Can you tell me who counseled you and what it was like? Did you find it helpful? Were you given any survivorship-related materials or resources?</p>
<p>3. Are you aware of any survivorship-related programs offered by your hospital or healthcare provider. Have you been involved in any of these programs?</p> <p>Follow-up prompts: How do you feel about the survivorship-related programs and resources that are available? Does your spouse feel differently? What do you wish your hospital had for survivors that they don't now?</p>
<p>4. Have you looked for any survivorship resources online? Social media? Apps? What do you wish was available online/mobile apps?</p>

Supplemental Online Table 2. Parent recollections of different phases of the transition off treatment and into long-term survivorship.

Quote #	Parent Quote	Parent ID
Parent experiences during treatment		
1	"It was physically taxing. You know you're not sleeping a lot. You're not taking care of yourself. You're reacting. You're really not in a position to be proactive because it's almost like you're giving yourself a pass on all of the physical things. Like, this is so much more important than my sleep or my diet or my health in general. So, it catches up to you every week... and your body has a way of saying: "No, no, no! We're dying. You have to let me rest."	01: father, leukemia
2	"You're in a place in those first couple of years where your child goes through some serious shit. And when they go through that, you naturally absorb all that negativity yourself and [you] change sometimes for the worse. You go into that place of: my child is still suffering. My child has lost all his hair and they're vomiting three, four times a day because of the chemotherapy. We can't have people over because [his] immune system is challenged and I don't want anybody touching him. So you have all these things that go on."	02: father, rhabdomyosarcoma
3	"Yeah it was it was very difficult in many ways.... I was in complete shock.... t was a huge transition for our family because he was supposed to start preschool.... So yeah it was a very it was very rough and there comes into play the whole like what do you do with your time? How do you work during that period? What do you do? It was very very disruptive to our family."	04: mother, glioma
4	"I started getting panic attacks shortly after [child] was diagnosed and I wasn't able to sleep either."	10: mother, neuroblastoma
5	"Emotionally, psychologically, it was rough, very rough to be honest.... You know physical trauma basically."	14: optic pathway glioma
Anticipating end of treatment		
6	"It's a sense of relief."	04: mother, glioma
7	"[It was] excitement we thought we were going to feel."	11: mother, leukemia
8	"[Anticipation of end of treatment] was a joyous ... occasion."	13: mother, leukemia
9	"All of the sudden [I had] more time."	17: mother, leukemia
End-of-treatment parent experiences		
EOT as more difficult than treatment		
10	"One of the hardest parts of this whole thing was the end of treatment. . . . You felt like you were supported by a bunch of doctors . . . then suddenly it's like you're dropped off a cliff or at least that's the way we felt. [The transition off treatment] was as tough a year as the year of chemo, maybe even harder, because you know you just feel like you're out there on your own."	15: mother, sarcoma

11	"[End of treatment] was very scary for me because I wanted her to be a survivor. I tried for my own stress to calm down but I think my level of stress actually got worse."	11: mother, leukemia
EOT bringing new anxieties		
12	"I just remember being fearful. You have that security of when you're on treatment and being at the hospital a lot. Even though we didn't like being there—it's uncomfortable—we were being followed, checking blood work, they're doing scans more frequently. All of that and then just kind of being let go. I remember being pretty nervous about that."	20: mother, sarcoma
13	"This may sound silly but there was a withdrawal. When you lean on the nurses and doctors as much as we learned to do on treatment, it was kind of scary."	18: mother, leukemia
14	"When we ended treatment, it's obviously scary because you go from seeing these doctors multiple times a week, multiple blood checks, and kind of through the treatment process you're getting constant reassurance that things are working and things are fine."	16: mother, non-Hodgkin's lymphoma
Security of clinical relationships recedes		
15	"You're suddenly off treatment and all the support you've had from doctors, nurses is gone."	16: mother, non-Hodgkin's lymphoma
16	"I feel like initially it was hard because you go from, 'OK she's having chemotherapy every day,' to nothing. And then what do we do next?"	6: mother, leukemia
17	"It kind of feels like they just drop you."	4: mother, optic pathway glioma
18	"I felt pretty alone."	8: mother, leukemia
Security of clinical roadmaps recedes		
19	"We don't know where to go. . . . We're kind of left to figure things out on our own."	3: father, medulloblastoma
20	"You sort of feel like you're a ship in open waters."	13: mother, leukemia
21	"I expected it to be like treatment, like here is your roadmap, and I didn't get that from the hospital."	19: mother, leukemia
Social support changes after EOT		
22	"Your friends just aren't the same after you get out and you don't look at the world the same."	7: mother, neuroblastoma
23	"Friends and family just can't wrap their brains around [EOT being difficult]."	15: mother, sarcoma
24	"There are things that [my child's] friends, my friends, just don't get and understand about [EOT being difficult]."	9: mother, leukemia
Preparation for EOT		

25	“Transition still to this day is very difficult. When we were discharged from the hospital we were prepared for what to expect medically, what we should be watching for in terms of fevers and what to watch for until his counts came back and we were prepared for what we needed to do and who to call for anything like that. The emotional and mental toll that it took on all of us though... there were no resources given to us as to where we needed to go or who we should see.”	12: mother, non-Hodgkin's lymphoma
26	“Besides getting the new roadmap for off-treatment, I don't feel like there was a whole lot of preparation. It was just, "You're not going to need to come see us as much.”	18: mother, leukemia
27	“Our oncologist and nurse practitioner had kind of been preparing us [for EOT and survivorship] from day one which I think is key even when you're in the beginning of it. They'd been preparing us for the transition to survivorship and that transition of care.”	6: mother, leukemia
28	“I don't know if there's a way to really prepare. . . . I don't think anyone could've really prepared us for [EOT].”	3: father, medulloblastoma
29	“After treatment ended, I probably should've got therapy because psychologically you're so different.”	7: mother, neuroblastoma
30	“I think just getting therapy, that's the hardest one because at the end of treatment the post-traumatic depression happens. It happens, and I think everybody needs to actually acknowledge it.”	11: mother, leukemia
Transition into long-term survivorship		
Anticipating long-term survivorship challenges		
31	“We're almost to the two-year mark. So now we have to worry about other things. So now I'm starting to be more concerned about the long-term. We're not just worrying about, 'OK let's get through the next 18 months to 2 years.' But now we're ready to worry about the next five years or the next ten years. What can we do for him until he turns 17? What can we do when he turns 27? That's where we're starting to go with now. I don't feel like worrying about the short term anymore. I'm now starting to worry about the long term and what it's going to be like when he's an adult and teenager when I'm not there all time.”	12: mother, non-Hodgkin's lymphoma
32	“I think I have an awareness that things are probably going to pop up at some point. So, the fact that we did so well for eight years and then it was like, wow, OK, now [health problems] are starting to pop up.”	8: mother, leukemia
Remaining present in face of long-term challenges		
33	“I would say we probably live more on the side of the fence of, 'Let's really focus on today.' Like, what can we do today that's going to be the best thing for her now... It's more short term. We're going to cross bridges when we get there.”	3: father, medulloblastoma
Focus on preventive health behaviors		
34	“A big push for us now [4 years since EOT] with him is to be active. . . . We really push him to be active because that's going to do him well. . . . I want to make sure that he consumes a lot of vegetables and fruit because I want him to have that kind of general health behavior that we should all have, but he's going to need it even more.”	9: mother, leukemia

35	"The first couple of years [after EOT] were hard for exercise because she didn't have any endurance and her legs would hurt a lot. So I would say two years or three years after treatment was when she was finally ready and able to do stuff."	15: mother, leukemia
Lack of information in survivorship care		
36	"I did not feel like there was a whole lot of preparation."	18: mother, leukemia
37	"[There was] not a lot of ongoing information afterwards."	20: mother, rhabdomyosarcoma
38	"I was not very pleased with the information we were given during or after treatment."	4: mother, optic pathway glioma
39	"[Our survivorship care plan] throws all these things out there and it's a little too much. I don't know. I would like some counseling. I would like them to talk about things like exercise and health. Just a healthy way of life. Things you can do to mitigate the late effects that the kids are going to see and specifically with leukemias and brain tumors, we need more talk about the cognitive late effects."	19: mother, leukemia
Parent assumptions about clinical survivorship programs		
40	"I'm just not aware of what I don't know. Maybe I didn't ask the right questions."	5: mother, sarcoma
41	"I imagine they do have [preventive health] resources that I just don't know about."	15: mother, sarcoma
Desired resources		
42	"As one parent summarized, "I think just having the doctors acknowledge that ... after diagnosis you can do things that are going to help."	7: mother, neuroblastoma
43	"So it would almost be like helpful for me for another doctor or nurse practitioner to be the one to have that conversation because it would reinforce what I'm saying."	8: Mother, Leukemia
Gender roles		
Gendered division of labor		
44	"The information flows through [my wife]. She'll tell me, 'Hey, this is something that's really important. . . . I just trust her.'"	1: father, leukemia
45	"[My wife] has had most of those conversations with doctors and I help her execute that on a daily basis. But I take the back seat in terms of that and just help and support whatever she wants to do."	2: father, rhabdomyosarcoma
Lack of father social support		
46	"I don't think through this process that dad's are championed a ton, right? You know, there are 'Momcologists' and all those things and just to be honest, like, yeah, I didn't see a ton of dads [in parent support groups]."	3: father, medullablastoma

47	<p>“There's not a lot of support for dads. Even though they love their children just as much as the moms do, they deal with it differently than moms. It's a totally different experience. And there's a lack of support for them.”</p>	14: mother, optic pathway glioma
Gender roles structuring childhood cancer experience		
48	<p>“I think he had an extremely different experience than I did. You know because I went to [treatment] alone with [child]. . . . He has a job and everything, so I just don't think we had the same experience.”</p>	15: mother, sarcoma
49	<p>“I'm his mom. Not that dads don't know best but you know I was the parent that was there the majority of the time. I was the one that lived in the hospital. I wasn't going back to work. And I was the one who experienced it all. Not that my husband didn't do anything, but you know he had to go back.”</p>	12: mother, non-Hodgkin's lymphoma