

Potential Benefits to Families, Children, and Adolescents Enrolled in Longitudinal Qualitative Research

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Table 3.
Benefits Reported by Participants

<i>Themes</i>	<i>Definitions</i>	<i>Exemplar quotations</i>
Study was helpful	Simple statement that the study was helpful	03D, 15-year-old: "I think it helped me indirectly." 22S2, 17-year-old: "I mean, probably good because it helped us get through the transplant."
Opportunity for introspection or reflection	Prompting participants to consciously think about what had happened to them over the course of a year	05D, 14-year-old: "It [the study] caused me to think about more things I didn't think I would think about." 22P, 16-year-old: "It helped me to reflect on everything I was going through." 22M: "The study made you think; you know . . . It made me think about things in length and not just on the surface. They were thought-provoking questions, and it made you research yourself."
Opportunity to talk	Being able to talk about their experience and share their story	AA03M: "I think if they [kids] talked at all and expressed themselves, it had to help. Any time they discussed it without pressure and they felt comfortable and could say whatever they wanted to say, I think it helps." 12HS1, 16-year-old: "I feel better. I had someone to talk to." 01D, 16-year-old, developmentally delayed: "It helped me to talk about how I gave [patient] my bone marrow and all." 04D, 17-year-old: "It feels actually pretty good . . . cause I get to talk about my sister and everything."
Opportunity to be altruistic	Feeling personal benefit from knowing that their participation may help others	23F: "There was no way I was not going to do it because, if only a little bit of what you have learned from us could help other families, help them deal with it, it is all well worth it." 26HS1, 19-year-old: "I am glad I could help out other families that may experience [a transplant] or are experiencing it." 05P, 16-year-old: "It's just a good thing to help other families. It doesn't really bother me to talk to you."

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<i>Themes</i>	<i>Definitions</i>	<i>Exemplar quotations</i>
Emotional outlet	Serving as an emotional outlet. Participants used such words as “express,” “feelings,” “open,” “relief,” “closure,” and “therapeutic.”	<p>12HS1, 16-year-old: “I was able to express my feelings, and I thought about the different things . . . I think it helped a lot of stuff come out in the open; everybody [the entire family] wouldn’t hold their feelings in anymore.”</p> <p>04P, 16-year-old: “If you have something you need to say, you can say it and just get your feelings and stuff out.”</p> <p>22S3, 14-year-old: “”The good part was that I had the feeling to express also about the situation . . . It was good expressing ourselves.”</p> <p>AA03P, 16-year-old: “I guess it had a good effect because everybody really got their feelings out and kind of changed.”</p> <p>04GF: “It helped me a lot to get a load off my chest.”</p>
Gained perspective	Getting an added or an “outside perspective”	<p>23M: “I’ve enjoyed getting to know you within this past year because you’ve brought light on some things and opened up eyes that were slightly closed. It is nice to have an outside perspective.</p> <p>23F: “. . . for them [the children] to be able to talk about this whole issue with an outsider with no preformed judgments or anything like that.”</p> <p>08M: “Just to think about an objective as well as professional point of view, you know, your angle to ask us things”</p> <p>26C2, 14-year-old: “I think it’s pretty helpful . . . getting information from everybody and seeing their point of view on how this situation went” (referring to family-decision models).</p>
Gained understanding	Gaining understanding about oneself and what was experienced during the transplant period	<p>05D, 14-year-old: “[There were] things I didn’t think about which, in a way, educated myself more about what I thought.”</p> <p>02HS, 15-year-old: “It [the study] probably helped her [donor] understand more . . . [the family decision models] helped me see the pros and cons of the whole thing.</p> <p>12HS2, 13-year-old: “I guess it helped . . . gave me somebody to inform me and to talk to other than family.”</p>
Creation of a safe space	Having a safe, trustworthy space to talk where confidentiality would not be breached	<p>01F: “You [the researcher] are about the only one I can really talk to about it because other people would probably run off to whom and whoever . . .”</p> <p>06F: “It is a real gentle way of discussing stuff . . . especially for people that are like myself that wouldn’t generally find themselves chatting to too many people about personal stuff.”</p> <p>12GM: “Definitely helped because it gave us a certain space where we could actually talk.”</p>

*The first number refers to the family. Families whose child had a hematological disorder had initials before the number, referring to the disorder: AA = aplastic anemia. Initials following the numbers refer to the person’s role: M = mother, F = father, P = patient, D = donor, S = sibling, HS = half-sibling, and GM = grand-mother. When there is more than one sibling, half-sibling, or cousin, each is identified by a number after the letter, e.g., “S2” for the second-oldest sibling.

Table 4.
Frequency of Benefits

<i>Attitudes</i>	<i>Parents, stepparents, grandparents</i>		<i>Patients <13 years old ≥13years old</i>		<i>Donors <13 years old ≥13 years old</i>		<i>Siblings, half-siblings, cousins <13 years old ≥13 years old</i>		<i>Total</i>
	<i>N = 32</i>	<i>N = 1</i>	<i>N = 8</i>	<i>N = 4</i>	<i>N = 5</i>	<i>N = 6</i>	<i>N = 14</i>	<i>N = 70</i>	
Opportunity to talk	10 (31)		1 (13)		4 (80)	1 (17)	3 (21)	19 (27)	
Safe space	4 (13)							4 (6)	
Opportunity to be altruistic	13 (41)		2 (25)				2 (14)	17 (24)	
Gained understanding	1 (3)		1 (13)		1 (20)	1 (17)	4 (29)	8 (11)	
Emotional outlet	5 (16)		2 (25)				4 (29)	11 (16)	
Introspection or reflection	12 (38)		2 (25)		1 (20)	1 (17)	3 (21)	19 (27)	
Gained perspective	6 (21)			1 (25)	1 (20)		2 (14)	10 (14)	
Found helpful	9 (28)		4 (50)	1 (25)		2 (33)	3 (21)	19 (27)	
Total mention of benefits	60	0	12	2	7	5	21	107	

Table 5.
Concerns

<i>Five concerns</i>	<i>Definitions</i>	<i>Twelve mentions of a concern by 11 (16% of) participants in 8 (38% of) families</i>
Didn't like one aspect of the methodology	Face-to-face too personal	02M*: "I avoided this last part face to face because dealing with what we are dealing with now still is just is, you know, hard . . ." 26D: I think I like over the phone better. I really don't like talking person to person.
	Asked the same questions during every interview	The researcher said to 20M, "I know your son said—that's why I am not speaking to him—he only did it [the third interview] because you promised it would be the last time." The researcher had been asked by 03M to stop interviewing her children because they were tired of the same questions. When the researcher asked if the kids were happy about this, 03M answered, "Yes." 26D: "It is like when they ask me those questions, the same one over and over."
	"Weird" to have the researcher ask questions	26C4: "At first, it felt kind of weird because I was the last to know, so, I didn't have much to talk about." 22D: "It was kind of weird because it was like this lady asking me a bunch of questions . . . it got normal . . . didn't really like have a problem with it"
	Boring	26C2: "It was a little bit boring."
	Quantitative section	23S1: "I didn't like that yes or no thingy."
Experience too overwhelming to participate	Reports family member too overwhelmed to participate	30F: "I think she was a little overwhelmed at the moment. Now, probably would be different for her."
Intrusive	Asks personal questions about participants' lives	23F: "I am really secretive about my life. I don't like people knowing what is going on in our lives and all that stuff . . . initially I didn't know how to handle it" (This father indicated in the end that he found the study helpful.)
Sad	Caused the participant to be sad	11D: "It made me feel sad about what was happening to my brother [the patient]."

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