

**Table 3.** How HCPs respond to social media use.

POSITIVE RESPONSES		NEGATIVE RESPONSES	
<i>Theme</i>	<i>Example</i>	<i>Theme</i>	<i>Example</i>
<b>Answered questions and provides additional information</b>	<p>“The doctor listened to our concern and discussed it with his colleagues and they discussed it with us. It made me feel they were concerned about my child and me.” (Participant 53, parent of a child with AML, questionnaire)</p> <p>“...not that I wanted to challenge my doctor at all, but to say, okay, can you explain to me you’re thinking of doing this instead of these? And then when she did, I’m like, okay, great, perfect. That’s what I needed to know.” (Participant 68, parent of a child with neuroblastoma, interview)</p>	<b>Disregarded questions or avoided discussion</b>	<p>“I think you can find stuff but [doctors] don’t want to hear it.” (Participant 23, parent of a child with osteosarcoma, interview)</p> <p>“I did worry about [the conflicting information], and I still have questions to this day unanswered.” (Participant 54, parent of a child with neuroblastoma, questionnaire)</p>
<b>Listened and showed interest in what parent learned online</b>	<p>“His team has told me multiple times that they really value my input and the research that I do...on his behalf.” (Participant 27, parent of a child with ALL, interview)</p>	<b>Answered questions but seemed displeased</b>	<p>“Doctors are intimidating. They can smash your hope in a second with an eye roll and ‘unproven.’” (Participant 29, parent of a child with chordoma, questionnaire)</p> <p>“...my problem is they listen to me and then they blow me up.” (Participant 106, interview)</p>
<b>Affirmed importance of</b>	<p>“...they recommended some groups for me to join and, you know, I have a great team. The case worker told me to go online, do your own</p>	<b>Became angry</b>	<p>“The doctor yelled at me on the phone for trying to push having the tumor biopsied or</p>

<p><b>parental education</b></p> <p>research, ask questions..." (Participant 13, parent of a child with ALL, interview)</p>	<p>removed sooner. I told him I was getting a second opinion and he ended the conversation pretty much instantly." (Participant 48, parent of a child with neuroblastoma, questionnaire)</p>
<p><b>Offered to modify treatment or refer for second opinion</b></p> <p>"They were like you can always ask for a second opinion, we recommend it." (Participant 16, parent of a child with rhabdomyosarcoma, interview)</p> <p>"Our NPs hadn't heard of a correlation between the medication and this side effect, but our oncologist had and she supported us in changing the schedule to try to rule this issue in/out." (Participant 61, parent of a child with ALL, questionnaire)</p>	<p><b>Told parent not go online again</b></p> <p>"[Our doctors said] "You should not be a Google doctor. You should not go online and worry about that stuff." (Participant 26, interview)</p> <p>"I think sometimes our small petty questions seem super petty to them, but seems so big to us, to where they tend to ignore or be like, 'Well, I'm making the right decisions for your kid, can you not just go with it stop doing your own medical research.' But again, as a parent, we spend all of our time with our kids. So we see the changes, we want to know." (Participant 59, parent of a child with ALL, interview)</p>
<p><b>PROMOTING TRUST</b></p>	<p><b>NEGATING TRUST</b></p>
<p><i>Theme</i></p>	<p><i>Theme</i></p>
<p><b>Openness to social media discussions</b></p> <p>"I trust that what our oncologist knows is best for him. She's very open to discussion." (Participant 3, parent of a child with ALL, questionnaire)</p> <p>"I trust our oncologist. We have an open dialogue and he values my knowledge about my</p>	<p><b>Unwilling or disinterested in discussing social media</b></p> <p>"I want doctors to hear me out when I mention vitamin C infusion. When I present them with newer research, I want them to consider it, look into it, and come back with information. Disagreements are fine, but I don't want opinions from something they learned 20 years ago." (Participant 29, parent of a child with</p>

	<p>son's health. I am always seeking out new information to help my son through this through research, conversations, and trial and error.” (Participant 27, parent of a child with ALL, questionnaire)</p>		<p>chordoma, questionnaire)</p> <p>“I don’t think the doctor knows how knowledgeable we have become about this disease and how much research we have done. I doubt they know how many personal stories we have heard from people in similar situations.” (Participant 48, parent of a child with neuroblastoma, questionnaire)</p>
<p><b>Honesty, transparency and humility</b></p>	<p>“An open line of communication and the ability to listen without thinking they know everything.” (Participant 27, parent of a child with ALL, questionnaire)</p> <p>“...that was beneficial, because then we were able to educate our doctors and they looked it up and they were like, ‘Oh, shoot. No. You’re not supposed to take that together.’” (Participant 30, parent of a child with ALL, interview)</p> <p>“A couple of oncologists that we had [said], ‘I can’t answer that. That’s a great question. I don’t have an answer,’ but that consistency of that is really what gained my trust because I knew they weren’t going to give me false hope.” (Participant 4, parent of a child with medulloblastoma, interview)</p>		<p><b>Lack of honesty, transparency and humility</b></p> <p>“I would ask my primary oncologist who was with us since the beginning, I would ask him questions about, like, his Curie score, I ask him about, you know, urine testing and things of that nature, and it wasn’t validated in clinic. He would just brush it off as ‘it’s no longer valid testing methods’, and I didn’t need to worry about it. And I’m like, but every other person posting on Facebook has these tests.” (Participant 54, parent of a child with neuroblastoma, interview)</p> <p>“...we knew there weren’t answers for the questions that we had often because it was new territory for everyone. But unfortunately our physician never wanted to say that.” (Participant 68, parent of a child with neuroblastoma, interview)</p>
<p><b>Shared decision-making</b></p>	<p>“I share online resources [with the doctor]. Therapies others are using, studies and trials</p>		<p><b>Unilateral decision-making</b></p> <p>“We’ve had something like that happen and we asked, you know, ‘What happens if we don’t</p>

<p>others are using, etc. that they may not see right away.” (Participant 23, parent of a child with osteosarcoma, questionnaire)</p> <p>“Yes, they were very understanding. Said they didn't know a lot about it but if I wanted to try it, they would support me.” (Participant 126, questionnaire)</p>	<p>sign this?’ And they said, ‘We'll strip you of your medical rights,’ and we were like, ‘Oh my God, okay, I will sign the paper.’” (Participant 3, parent of a child with ALL, interview)</p> <p>“I felt like I didn't have a lot of trust...because I was reading all these other treatment options online and yet they were not being presented to me.” (Participant 54, parent of a child with neuroblastoma, interview)</p> <p>“...she makes me feel like a little person...like, she'd been doing this for 14 years. She knows what she's doing. She doesn't need our help.” (Participant 59, parent of a child with ALL, interview)</p>
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