

Table 2. Benefits and risks of social media use as identified by parents of children with cancer.

BENEFITS		
<i>Theme</i>	<i>Subtheme</i>	<i>Example</i>
Connection	<i>Access to firsthand personal information (e.g., other families' cancer journeys)</i>	<p>“I wanted access to real-life experiences and outcomes so that we had an idea of what our future might look like.” (Participant 7, parent of a child with ALL, questionnaire)</p> <p>“I cannot imagine going through the past 5 years without [social media], to be honest. The doctors and nurses are bound by HIPAA and can't really connect families well.” (Participant 23, parent of a child with osteosarcoma, questionnaire)</p>
	<i>Hope (e.g., learning that other children were cured or had a good response to a certain therapy)</i>	<p>“...their daughter was at the end of treatment and our daughter was starting it, and just being an example of there is a light at the end of the tunnel...” (Participant 11, parent of a child with medulloblastoma, interview)</p> <p>“The interactions of Facebook are hope. When doctors say she's out of options, 'Facebook' says 'try this.' Will it work? TBD. But it's hope when our medical team continually gives us none. This could turn out to save her life.” (Participant 29, parent of a child with chordoma, questionnaire)</p>

Validation (i.e., of one's own experiences and emotions as normal, appropriate, etc.)

“...there's 50 moms corroborating what I'm going through with my daughter...” (Participant 6, parent of a child with neuroblastoma, interview)

“...I do feel like we're all, even around the world, all of our kids are given the same medications, that's reassuring.” (Participant 59, parent of a child with ALL, interview)

“[I]t's just a space where you can say, you can say it sucks that I have to be here and dealing with this, and no one's going to tell you, ‘Well, it's your child, you shouldn't say that.’ I know it's my child, but I can feel that way. It's okay.” (Participant 106, interview)

Solidarity (i.e., with other families of children with cancer)

“It's made me realize I'm not alone and there's people out there who may be wondering the same.” (Participant 3, parent of a child with ALL, questionnaire)

“...you form this really weird bond and you cheer each other on through tough patches and you celebrate their victories, you know, when their kids are doing good, and it's just an amazing relationship.” (Participant 27, parent of a child with ALL, interview)

“I learned that even though so many children share the same diagnosis as my son, our paths are so different. And the amount of love and support in these groups is unmatched.” (Participant 55, parent of a child with ALL, questionnaire)

Communication

Self-expression and documentation (e.g., through writing and storytelling)

“I do not find my updates as a burden at all. They are better than any therapist I've been to.” (Participant 29, parent of a child with chordoma, questionnaire)

“My goal is many years from now to get her CaringBridge made into a book. So she can have that history. I'm not sure I would have documented her journey for her later in life if it weren't for social media.” (Participant 68, parent of a child with neuroblastoma, questionnaire)

Updating friends and family (e.g., to decrease communication burden, increase efficiency)

“...I did not want to get physically contacted by hundreds of people about my daughter. I was able to get my point across without having to physically talk to anyone.” (Participant 6, parent of a child with neuroblastoma, questionnaire)

Counteracting isolation (e.g., “lifeline to outside world”)

“...our connection with really a lot of the outside world on a larger basis was using CaringBridge.” (Participant 11, parent of a child with medulloblastoma, interview)

“[When] you can't leave your house, it's an opportunity to talk with your other acquaintances or friends.” (Participant 31, parent of a child with ALL, interview)

Information

Decisional support (e.g., inform decision-making, guide questions)

“It encouraged me to push through those side effects because I realized I was seeing that there [were] kids who were surviving when they were taking this drug.” (Participant 23, parent of a child with osteosarcoma, interview)

“Some [doctors] are very straightforward and share many details, but others keep a lot to themselves and only tell you what they want you to know... We have found a lot of questions to ask the doctors from Facebook, that we never would have known to ask if we had just looked online or listened to what they said.” (Participant 48, parent of a child with neuroblastoma, questionnaire)

“We trust our doctors implicitly, but they aren't gods, can't be omnipresent, so the lived experiences (ours, and other families) can help add nuance and detail to a situation to help a doctor make more informed recommendations.” (Participant 61, parent of a child with ALL, questionnaire)

*Treatment options
(e.g., second
opinions, clinical
trials,
complementary
and alternative
therapies)*

“...I need to know I exhausted all avenues of proper care for her or thought processes of care...”
(Participant 6, parent of a child with neuroblastoma, interview)

“I have one of the best pediatric cancer teams in the world, and they told me she was dying in January. She's still here and she had many good months. I now do my own research and drive the team with direction.” (Participant 29, parent of a child with chordoma, questionnaire)

“There are TONS of treatment options that are, and never will be presented...by my physician. Very frustrating [that] I have to spend hours on Facebook to find the most fitting treatment for my child, and I'm the one without a medical license.” (Participant 54, parent of a child with neuroblastoma, questionnaire)

“I always take the advice of my son’s consultants above what I find online. My search online merely consolidates my understanding of his diagnosis and treatment.” (Participant 7, parent of a child with ALL, questionnaire)

Education (e.g., filling gaps in knowledge, translating into “plain language”, enhancing ability to care for child at home)

“They're the ones with the answers when sometimes you can't get a hold of a doctor or a nurse right away to be like, ‘My kid has a fever. It was like 100.5, do I go in, do I not go in, what do we do?’ You know, there's little things like that, you know, that they just need reassurance from somebody else that's been there that, you know, done that like, ‘No. Take your kid to the hospital.’ You know, ‘You have every right to go to the hospital, just go.’ Or like, ‘No-no, just...give a little Tylenol and see if it's okay. If it goes away then, you know, you don't need to get those germs from the hospital.’” (Participant 30, parent of a child with ALL, interview)

“The information we have gotten from the Facebook groups has been the most useful in learning more specific details about what to expect and what questions we need to ask the doctors. These groups have drastically changed my knowledge base.” (Participant 48, parent of a child with neuroblastoma, questionnaire)

Empowerment (e.g., greater sense of control, way of taking action, mitigating helplessness)

“I felt more empowered knowing what I learned online. I honestly think I know more families of osteosarcoma [patients] from social media across [the] country than some of our oncology doctors here locally.” (Participant 23, parent of a child with osteosarcoma, questionnaire)

“...it feels like we're doing something when we go and actively try to find treatment options for them.” (Participant 54, parent of a child with neuroblastoma, interview)

“We as a family have had situations in a smaller hospital and so it was nice to be able to go to my Facebook group and be like, ‘Is this normal? Is this okay? Is this right?’ And then get a parent's opinion who says, ‘Absolutely not. Don't leave there, you know, stand your ground. I'm sorry you're going through this.’” (Participant 59, parent of a child with ALL, interview)

Advocacy

<i>Advocate for own child (e.g., access to treatment)</i>	<p>“I’ve pushed very hard for alternative options, many that go against hospital policy. Too many to list. But I’ve informed them we are pushing things directly into their G-tube. I am careful not to ask permission or opinions, because I know what they will be. I’m very assertive. They also know my blog exists, with 100,000+ followers, with daily updates, so I think that’s in my corner.” (Participant 29, parent of a child with chordoma, questionnaire)</p> <p>“I’ve always been the one to advocate for my kid. If I feel like something was not right, I tell the doctor, I’m not comfortable with that decision that you make. I don’t want to do that. And it’s just, I don’t know, I guess people trust them and they say, ‘Hey, I’m going to let them do whatever they want to do, and not question it.’ But you have to question, you know, because you know your child better than anybody else.” (Participant 52, parent of a child with neuroblastoma, interview)</p>
<i>Raise awareness (of childhood cancer)</i>	<p>“I’ve made it my goal to share my son’s journey to prove that childhood cancer isn’t rare. Social media has allowed me to educate those around us about all the side effects, treatment, and life with cancer as a child.” (Participant 27, parent of a child with ALL, questionnaire)</p>
<i>Fundraise for own family</i>	<p>“I fundraised almost \$4,000, and I absolutely would not have done that without social media.” (Participant 44, parent of a child with ALL, interview)</p>
<i>Contribute to research</i>	<p>“...every time there is research or something [online] I always volunteer for that...whatever good thing that comes from any research, it could benefit him and any other child.” (Participant 12, parent of a child with post-transplant lymphoproliferative disease, interview)</p>

RISKS

<i>Theme</i>	<i>Subtheme</i>	<i>Example</i>
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“Bad information”

Conflicting or contradictory information (i.e., from two or more sources)

“Early on I found a family in New Zealand (I’m in the U.S.) that has a living child with this cancer... I was told by our medical team that never happens. That was proof that my doctors didn’t know everything, and I could access more info than they could ‘non-clinically.’” (Participant 29, parent of a child with chordoma, questionnaire)

“Every time I have a concern, I google or use social media of some kind to educate myself on what others experience and then question our team of doctors.... never do the two answers match.” (Participant 59, parent of a child with ALL, questionnaire)

False information (i.e., information disproven by science, evidence, facts)*

“I’m often frustrated by people sharing poor information. For example, connections with sugar and cancer but the lack of understanding of how fast-growing cancer cells function. ... one woman, ‘the wellness warrior’ only wanted to use alternative medicine to treat her cancer. Both her and her mom died following this method. I'm concerned that other families may have rejected treatment due to this information.” (Participant 16, parent of a child with rhabdomyosarcoma, questionnaire)

“...we're not doctors, so we can't give medical advice, but so many feel the need to give because...we're moms, that's just what we do. But it's half the time it's not right.” (Participant 59, parent of a child with ALL, interview)

*Biased narratives (e.g.,
tending toward best- or
worst-case scenarios)*

“...a lot of moms online...often aren't good at representing more than their own experience.”
(Participant 44, parent of a child with ALL, questionnaire)

“...when [my child] was first diagnosed, I tried to research and every blog I came across, the kid died... My husband gets up and he's like, 'You're done. You're not allowed to look at this stuff anymore.'” (Participant 68, parent of a child with neuroblastoma, interview)

“...you have to keep that in mind when you filter through all these stories, some of them can come off as fear mongering, because they've had such a traumatic experience but their one story is a rarity... if you go through all these treatments, and your kid survives, then you unsubscribe because you no longer have a need, you're no longer seeking that help. So, all of those successful stories are pulled because people are no longer following or no longer commenting...”
(Participant 54, parent of a child with neuroblastoma)

*Overwhelming quantity
of information*

“I eventually reduced my research online, because I would go down rabbit holes of information. It ultimately impacted my mental health.” (Participant 16, parent of a child with rhabdomyosarcoma, questionnaire)

“There is a ton of information online. It can be scary to read statistics.” (Participant 27, parent of a child with ALL, questionnaire)

“I didn't get involved in Momcology or our local cancer parent community until about 9 months into treatment and a little into maintenance. I'm really glad it happened that way. I feel that allowed me to focus only on medical opinions and not have to filter out other noise.”
(Participant 44, parent of a child with ALL, questionnaire)

Emotional burden

Sadness and grief (e.g., vicarious trauma, investment in others' journeys)

"...it just got to be too much and so I had to leave because I couldn't handle all the sad stories."
(Participant 30, parent of a child with acute lymphoblastic leukemia [ALL], interview)

Time-consuming and/or isolating (e.g., takes parent away from "real" life not on SM)

"You know, there's two sides of every coin where you're spending so much time online, you're not paying attention to what's going on in the world." (Participant 6, parent of a child with neuroblastoma, interview)

"But it's also extremely draining. It's time consuming. There are update expectations."
(Participant 29, parent of a child with chordoma, questionnaire)

Survivor guilt

"...you feel bad when your child is the one that's doing well...their child is gone and your child is not." (Participant 35, parent of a child with ALL, interview)

"...we see our daughter as sort of this golden child of such a horrible disease because we just don't have it as rough as everybody else. ... I'm not saying it's smooth sailing, but – it makes you feel guilty in a sense because we all were given the same diagnoses, we all heard the same words from the doctor, your child has cancer, but yet our situation is not as extreme as others."
(Participant 68, parent of a child with neuroblastoma, interview)

Judgment

*Second-guessing
decisions*

“I felt a lot of pressure in that sense to make sure that I was making the right decisions and so I looked online, looking at other stories and seeing who would be okay and also knowing about people’s side effects, long term...” (Participant 16, parent of a child with rhabdomyosarcoma, interview)

“We were confused about what to do. We didn't want to not be compliant with what the doctor was wanting, but we knew we needed answers for our son and he was the number one priority.” (Participant 48, parent of a child with neuroblastoma, questionnaire)

“I deleted my posts because there was this influx of like, that is not a good test and why would you do that? And ‘that’s awful and you need something better that more accurately measures.’ And then that sends you into panic mode because you’re like, ooh, maybe we didn’t make the right choice.” (Participant 68, parent of a child with neuroblastoma, interview)

*Accusations of bad
parenting or child abuse*

“I tried to ignore information that I knew was false, but sometimes people tried to make me feel guilty for using chemotherapy and radiation.” (Participant 16, parent of a child with rhabdomyosarcoma, questionnaire)

“I had people posting on my son's Facebook page saying that by giving him chemo, that we were actually killing him.” (Participant 27, parent of a child with ALL, interview)

“I've had people message me...and be like, ‘You could have given this to your daughter, like letting her be vaccinated to start with.’ ... it's really hard for me to get people that tell me that what I'm doing is wrong.” (Participant 68, parent of a child with neuroblastoma, interview)

“I don’t want to say a backlash but [we] heard some negative comments from my family members, like [we] were trying to garner sympathy...” (Participant 13, parent of a child with ALL, interview)

“So, people are saying...really blatantly racist things, like blatant xenophobia...” (Participant 16, parent of a child with rhabdomyosarcoma, interview)

*Other forms of harassment**

“Trolls who push their beliefs for cannabis and CBD [are] annoying. I've figured out how to block those keywords on Facebook.” (Participant 27, parent of a child with ALL, questionnaire)

“...someone even asked me to like, "Why don't you cut her hair? Why are you letting it all out like that?" Criticizing just us as parents for the things that we do. Sometimes I feel like people are just, dumb is not really the right word, but kind of-. But just dumb and don't know the difference between appropriate and inappropriate questions. And I'm all about educating anybody who has questions.” (Participant 59, parent of a child with ALL, interview)

Privacy*

Misuse of personal information (e.g., information stolen or used for scams)

“[Y]ou never know who is going to take your child’s picture and...open a fake GoFundMe with your child’s photo. (Participant 13, parent of a child with acute myeloid leukemia [AML], interview)

“We didn't -- even organizations, we wouldn't let people take photos of her. It was only kind of as hair grew back in and stuff that we've loosened up a little.” (Participant 44, parent of a child with ALL, interview)

Loss of control (i.e., cannot control where personal information goes or how it is used once released)

“I think once you post anything on there that you have to understand the fact that it's out there, people can find it, people can read it, so if you don't want something out there, don't post it about your child.” (Participant 11, parent of a child with medulloblastoma, interview)

“I made the decision when I started writing and sharing online and all of that, that we kind of were an open book.” (Participant 27, parent of a child with ALL, interview)

“It's very easy to be like, sold out to the crowd of which you're sharing information with. ...the more you share about your family, the more you open up the space for negativity.” (Participant 54, parent of a child with neuroblastoma, interview)

“...don't put anything that you don't want to see it again because you're just going to see it over and over and over again...” (Participant 59, parent of a child with ALL, interview)

Inequity*

“...certain parents with privilege, different amounts of privilege, actually get pretty well connected in the community.” (Participant 4, parent of a child with medulloblastoma, interview)

“...the people who left for [this] part of treatment all had higher education and sought better options for their children...” (Participant 65, parent of a child with neuroblastoma, interview)

*Identified as an ethical concern by parents.