

“The Stakes Could Not Be Higher”: A Qualitative Study of Parental Social Media Use in Pediatric Oncology

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Abstract

Background: To describe how parents and families of children with cancer evaluate the benefits and risks of using social media (SM) and how they navigate disagreements between oncologists’ advice and information found on SM. Procedure: Parents of children who had been previously diagnosed with cancer, and who had used SM for a purpose related to that child’s health were recruited through SM sites and nonprofit organizations across the U.S. and were invited to complete questionnaires about their experiences using SM; a subset of participants also completed a follow-up in-depth interview. Open-ended responses and interviews were analyzed using thematic analysis. Results: 90 parents completed written questionnaires; 21 completed follow-up interviews. 70% described experiencing a situation in which information shared on SM conflicted with information provided by their child’s oncologist. Although 86% discussed it with the oncologist and 70% described the response as positive, 78% retained negative feelings about the experience. Openness to discussing SM, honesty, transparency and humility regarding the limits of medicine, and shared decision-making regarding information found on SM were connected with reported trust in the oncologist. Conclusions: Parents offered valuable insights regarding their experiences navigating SM, including 8 recommendations for how pediatricians might approach discussing parental SM use. Future studies will evaluate the utility of these recommendations for pediatric clinicians.

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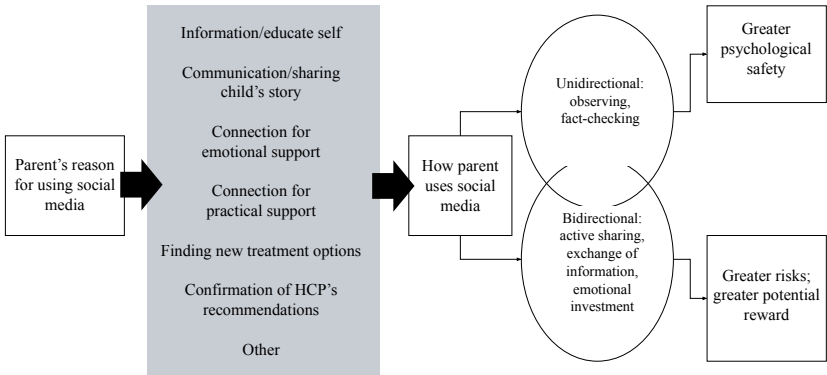
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Figure 1. How parents use social media affects perceptions of risks and benefits.



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Figure 2. How parents assess trustworthiness of information on social media and resolve tensions between information on social media and HCP recommendations.

