

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

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ABBREVIATIONS

HCP	healthcare professional
Pedi-TIPS	Pediatric-adapted Trust In Physician Scale
SM	social media

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.

INTRODUCTION

1 Families of children with cancer frequently turn to social media (SM) for information,
2 psychosocial support and connection, and material and financial support; one study estimated
3 that 80% of parents of young cancer survivors use SM daily.¹⁻³ Gage-Bouchard and colleagues
4 have done substantial work around parental SM use in pediatric oncology, defining categories of
5 health-related Facebook usage² (e.g., social support, advocacy, emotional strain), while others
6 have looked at the content of social support and the management of uncertainty via blogging by
7 parents of children with cancer.^{1,4-10} Contemporaneous studies have also identified unmet
8 information needs among parents of children with cancer, including prognosis, late effects, and
9 transition to survivorship, so it is perhaps not surprising that parents turn to SM to fill these
10 gaps.¹¹⁻¹³

11
12 A study of 40 parents of children with acute lymphoblastic leukemia (ALL) found that parents
13 turn to SM to meet information needs because the information is immediate, targeted to their
14 specific questions and concerns, and tailored to their roles as parents or caregivers.⁷ SM alters the
15 balance of power too: parents are no longer wholly dependent on clinicians for medical
16 information.^{3,14} One study¹⁵ that explored clinicians' experiences with parents seeking health
17 information online found that clinicians felt obliged to reallocate time in order to help parents
18 better understand the concept of "evidence" in medicine and to respond to perceived critique of

19 their practices. Parents, furthermore, inevitably encounter conflicting information, testing their
20 trust in their physicians' advice.¹⁵ Yet these challenges—navigating discordant information and
21 building trust in this age of SM and disinformation—have received scant attention in the
22 literature. We therefore sought to explore how parents evaluate the benefits and risks of using
23 SM and how they navigate disagreements between oncologists' advice and information found on
24 SM.

25

26 **METHODS**

27 **Eligibility criteria and study recruitment**

28 Non-profit organizations that support families of children with cancer and had a SM presence
29 were invited to share information about the study with their members via SM platforms,
30 websites, and listservs. Interested members then contacted the study investigators via email to
31 learn more. Prospective participants were eligible if they (1) were the parent or guardian of a
32 child who had previously been diagnosed with cancer, (2) had used SM for purposes related to
33 the health of their child with cancer, and (3) were able to communicate in written and spoken
34 English. Eligible participants were also asked whether they would be willing to participate in a
35 follow-up virtual video -interview regarding their experiences with SM. Participants were offered
36 a \$20 gift card for completing an initial written questionnaire and a \$30 gift card for completing
37 a follow-up interview. The dual design was intended to allow for a larger sample size and to
38 capture the perspectives of participants who might be reluctant to share their views in an
39 interview, as many parents may be drawn to SM for the relative anonymity and/or written
40 format. The target sample size was 80-100 questionnaire participants and 20-25 interview
41 participants based on similar studies, although saturation was considered the final determinant

42 for sample size.¹⁶ The study was reviewed by the SUNY Upstate Medical University Institutional
43 Review Board and declared exempt.

44

45 **Data collection**

46 The questionnaire was divided into 6 sections: demographic information; basic information
47 about the child's health; general SM use; use of SM related to childhood cancer; experiences
48 with disagreements between SM and advice from the child's oncologist; and understanding of
49 trust and the pediatric-adapted Trust in Physician Scale (Pedi-TIPS).¹⁷

50 A preliminary analysis of questionnaire responses was used to inform development of a semi-
51 structured interview guide. Interviews ranged from approximately 30 to 60 minutes in duration.
52 Each parent was asked an open-ended question about their family and journey thus far; 2-3 open-
53 ended questions based on the parent's written responses to the questionnaire, designed to allow
54 for sharing of experiences in more detail; 3 member-check questions based upon common
55 themes that emerged from the questionnaires (e.g., "Some parents in our study have said that...
56 What do you think about that?"); and 3 questions asking about advice for other parents, advice
57 for oncology providers, and perceived ethical issues. Verbal consent was obtained at the start of
58 each interview and participants were advised that they were free to stop the interview at any
59 time. Audio recorded interviews were then transcribed verbatim for analysis.

60

61 **Data analysis**

62 Quantitative data were analyzed using IBM Statistical Package for the Social Sciences, Version
63 26.0.¹⁸ Descriptive statistics were generated for all demographic information and questions
64 regarding frequency of SM use and platforms used. Mean, standard deviation, Cronbach's alpha,

65 and corrected item-to-scale correlations were performed for Pedi-TIPS. Open-ended
66 questionnaire responses and interview transcripts were analyzed using a thematic analysis
67 approach, supported by NVivo (Release 1.0) qualitative analysis software.^{19,20} First, 4 members
68 of the research team independently coded 20 questionnaires and then collaborated to construct
69 the initial coding scheme, which was agreed upon by all team members. Each questionnaire was
70 subsequently coded by 2 researchers. Areas of potential disagreement between coders were
71 examined by a third researcher and resolved through discussion and consensus. All researchers
72 met regularly to discuss and agree upon the grouping of codes into themes and subthemes and
73 relationships between themes, and to determine and agree when saturation had been achieved.²¹
74 The process was repeated for the interview transcripts, building on the code book generated for
75 the questionnaires. Records of all raw data, including memos and meeting notes, were kept. All
76 interviewees were also invited to provide feedback on the analysis via email; those who chose to
77 respond affirmed that the work reflected their experiences accurately.

78

79 **RESULTS**

80 Of the 128 who completed eligibility screening, 121 (95%) were eligible to participate, and
81 90/121 (74%) completed the entire questionnaire. Of those 90 participants, 38 (42%) expressed
82 interest in participating in a follow-up interview and 34 (38%) expressed interest in having their
83 child's oncologist participate in a follow-up study; 21/38 (55%) completed the follow-up
84 interview. Reasons for non-participation in the interview included decline in the child's health
85 (2/17), lack of time (5/17), and non-response to the interview invitation (10/17).

86

87 Table 1 presents demographic information regarding participants and their children with cancer,
88 as well as characteristics of participants' SM use. Most participants were female (93% of
89 questionnaire participants; 96% of interview participants), 25-44 years old (80%; 77%), and
90 white (86%; 82%); questionnaire participants were less likely to be highly educated than
91 interview participants (51% of questionnaire participants held a bachelor's degree or higher vs.
92 77% of interviewees). The mean total score on Pedi-TIPS was 45.74 (SD 6.75), with a median
93 range of 46 (range 17-55). The scale was internally consistent with a Cronbach's alpha of 0.89.
94 Previous studies reported a mean total score of 45.4 (SD 6).¹⁷

95

96 More than 80% of participants agreed that they used SM for one or more of 4 reasons: to connect
97 with other families for emotional support; to connect with other families for practical support; to
98 educate themselves about their child's illness; and to share their child's story with family and
99 friends. Approximately half reported using SM to find new treatment options and 40% reported
100 using it to confirm the information provided by their child's doctor. One-third also stated that
101 they used SM to raise money to help cover the costs of their child's care.

102

103 **Benefits, risks and ethical issues**

104 Most parents (64/90, 71%) described that SM had been helpful to them personally; 15 (17%)
105 described feeling that SM had been both helpful and harmful; and 8 (9%) described feeling that
106 SM had only been harmful. When asked about SM's impact on their children, 68 (76%) thought
107 it had ultimately been helpful and none thought it had been harmful. The remainder were unsure
108 or thought it had done neither. A minority (11/90, 12%) described feeling that it improved the

109 quality of care that their children received awareness of and access to treatment options that the
110 parents felt would not have been sought or obtained without SM.

111

112 The idea that SM can offer an “overwhelming” orientation to the “world of cancer” was echoed
113 by many parents. Their reasons for using SM guided how they used it, which in turn influenced
114 their perceptions of risks and benefits (see Fig. 1). Parents who preferred to stay in an
115 observational role (e.g., “lurking”) for the purposes of gathering information and learning from
116 others’ experiences, tended to describe SM as overall more positive and to report fewer
117 perceived risks of SM use. Parents who were deeply engaged in exchanging information and/or
118 who reported forming meaningful relationships on SM also described incurring subjectively
119 greater risks but also greater rewards.

120

121 Benefits and risks (see Table 2) were each grouped into 4 and 5 themes respectively (connection,
122 communication, information, and advocacy; “bad information”, emotional burden, judgment,
123 privacy and inequity; each with multiple subthemes). Although parents frequently mentioned
124 privacy as a concern and discussed the loss of control of posted material, none of the participants
125 discussed fears regarding their children’s privacy later in life (i.e., whether their children would
126 object to or experience consequences from having health information made public). One
127 participant commented, “Sometimes [my daughter] prefers to not have everyone know
128 everything. But with childhood cancer - no one had any idea what was involved and [posts on
129 SM are] educating hundreds of people who had no clue. Sometimes [she] would rather be
130 anonymous. But at least people don't come up to her anymore and ask how she is doing.” A few

131 parents described their hopes that their SM use would provide a record of the child’s journey for
132 the child to have later in life.

133

134 **Credibility, conflicting information and trust**

135 Several themes recurred when parents discussed how they assess the credibility of
136 trustworthiness of information shared via SM (see Fig. 2). Most parents tried to verify
137 information, often with the oncologist but also with their own partners, family and friends; with
138 other families of children with cancer; and/or with “credible” sources, such as hospital websites
139 and online medical journals. They reported trusting firsthand, personal experience (“...people
140 who have ‘been there’ are immediately more trustworthy...”), especially when it contained a
141 high level of detail and was recent; and information that reappeared in several different places
142 (“Number of ‘verifiable’ success stories is probably my number one. A statement saying ‘we’ve
143 cured over 50,000 cancers!’ does nothing for me. ... But...where it’s person after person saying
144 ‘I’ve tried this after a terminal diagnosis, and now my tumors are gone’... that’s way more
145 convincing.”). They also considered the relative urgency of their concerns in relation to the
146 information sought or found and the potential impact of the information, with some parents
147 reporting more willingness to trust information or try an online recommendation for non-urgent
148 or low-impact concerns and other parents reporting the opposite. Two distinct subsets of parents
149 did not describe following any part of the pathway in Figure 2 and instead said that they relied
150 upon intuition or prayer, or that they “never trust” SM.

151

152 Although parents did raise concerns about misinformation, as above, these complaints were less
153 common than expected. Parents cited misinformation as influencing emotions more than

154 decisions. A more pervasive concern was the exchange of information regarding variation in
155 practices between oncologists and children’s hospitals. Many parents described leaving these
156 exchanges feeling that their center “does it wrong” and they sometimes felt judged by other
157 parents for not seeking care from hospitals identified (by other parents) as the “best” places for
158 particular tumor types. A few parents at smaller programs expressed parallel concerns about lack
159 of local expertise. Lack of choice—either in the program and hospital or in the child’s primary
160 oncologist—seemed to contribute to skepticism and mistrust.

161

162 Sixty-three (70%) questionnaire respondents described having experienced a situation in which
163 information shared on SM conflicted with information provided by their child’s oncologist.
164 Several other parents also explained how they felt SM had helped them recognize a
165 misdiagnosis, prior to their child’s cancer diagnosis, and empowered them to insist on further
166 evaluation for their child. Examples of conflicting information were diverse, involving diagnosis,
167 monitoring, treatment options, adverse effects, supportive care, quality of life, and
168 complementary and alternative medicine. For example, one parent described being questioned by
169 other parents online regarding her daughter’s physician’s decision to monitor for recurrence with
170 ultrasound, rather than CT or MRI. Another parent discovered that radiation was sometimes
171 effective for her child’s disease, although she thought her oncologist had said that it never
172 worked. Some parents described situations in which they did not recall being told about possible
173 adverse effects but learned about them through SM. Others explained that SM showed them that
174 there is great variation in how pediatric oncology programs approach restrictions related to
175 everyday life (e.g., safety of swimming during treatment), with some programs being much more

176 conservative and others much more relaxed. This variation led them to realize that not all
177 healthcare advice was evidence-based.

178

179 Most parents (54/63) said that they approached the oncologist or another member of the pediatric
180 oncology team to ask about the conflicting information. Of those who chose to ask about it, most
181 (38/54) also believed that the response from the healthcare team was positive: the healthcare
182 professional (HCP) listened, showed interest in the parent's research, answered questions
183 willingly or agreed to do further research, and/or affirmed the importance of parents educating
184 themselves (see Fig. 1). Others described negative reactions, including avoidance and anger,
185 which in the most extreme cases led the parents to transfer care (see Table 3). Independent of
186 whether they chose to approach the HCP, many parents (49/63) continued to have negative
187 feelings (e.g., anger, confusion, fear) that they attributed to the conflicting information.

188 However, parents who did approach their HCP also identified 4 elements of positive HCP
189 responses to discussions of information gleaned from SM and 3 ways in which HCPs were able
190 to build trust through their responses. These were mirrored by ways in which HCPs responded
191 negatively and negated trust (Parents who did *not* speak with their HCP consistently reported
192 feelings of confusion and distress, and they sought to regain a sense of control by reaching out to
193 other sources to verify or refute the conflicting information (see Fig. 2).

194

195 Finally, participants' suggestions for how pediatricians might approach discussing parental SM
196 use were grouped into 8 concrete recommendations.

197 1. Be open to parents asking questions and raising concerns based upon information from social
198 media.

- 199 2. Be honest with us about what you know and don't know. We will probably Google
200 everything you say or at least check it with our social media networks and other parents. It's
201 not personal and it doesn't mean we don't trust you. In fact, when we find things we don't
202 understand or get advice we aren't sure whether to follow, we want to be able to trust you to
203 help us work through it.
- 204 3. Consider using social media yourself in order to better understand families' perspectives and
205 see the online world through our eyes—but if you do, be cautious and take care of yourself.
206 social media can be emotionally overwhelming, even for doctors.
- 207 4. Educate yourself about complementary and alternative therapies, including nutrition and
208 behavior, and about life as a cancer survivor: these gaps in what you talk to us about are one
209 reason we turn to social media.
- 210 5. Speak slowly and use plain language. This is another reason we turn to social media.
- 211 6. Know that it's okay if sometimes we prefer to look up what you said, rather than asking you
212 to explain it immediately: this can help us exercise some control in a situation where we
213 often feel powerless.
- 214 7. Treat each family as an individual. We know from our own social media research that other
215 families may be facing more terrible diseases or poorer prognoses and sometimes we feel
216 guilty if our child is doing relatively well. When we talk to you, we need you to take some of
217 that burden away and recognize that, for us, whatever we are going through *is* the worst-case
218 scenario.
- 219 8. Work with your hospital to develop formal guides and education to help us navigate social
220 media, especially how to evaluate the credibility of information online and spot “bad”

221 information, and how to take advantage of online support groups and other psychosocial
222 resources.

223

224 **DISCUSSION**

225 Writing about the patient-physician relationship in the 21st century, Grob and colleagues²² have
226 argued that “the principles underlying the patient-physician relationship must shift from simply
227 emphasizing patients’ adherence to cultivating patients’ ability to contribute to the development
228 of care plans that reflect their own values and preferences.”^{22(p1347-1348)} This desire for reciprocal
229 trust and truly shared decision making underpinned many of the concerns of the parents whose
230 voices are represented here.

231

232 Our study highlights many opportunities for improving communication between families and
233 clinicians regarding SM use and for educating families and clinicians alike. It is clear that the
234 parents in our study felt a significant burden of responsibility when it comes to navigating SM
235 and weighing recommendations found online. The stakes are tremendously high, and parents feel
236 pressure to make the right decision at all levels: when to post, when to question, when to trust,
237 when to share information with their child’s physician, and when to seek a second opinion or
238 transfer their child’s care. Parents also seek information that is accessible and comprehensible.
239 Even when they feel comfortable asking questions, they may value the choice to search for their
240 own answers, part of retaining agency in difficult circumstances, as well as the ability to learn
241 from other parents’ decision-making process; and they are interested in knowing how to do so
242 effectively, while also protecting their own mental health and well-being.²³⁻²⁶

243

244 Our findings regarding how parents appraise information exchanged online are consistent with
245 other studies, which also concluded that people tended to trust those with similar experiences and
246 perspectives as themselves and that repetition of the same information from different sources
247 enhances the perceived credibility of that information.^{7,26} Misinformation was less pervasive a
248 theme than we expected, but this may be supported by a prior study that found about two-thirds
249 of parent posts regarding childhood cancer are medically accurate.⁶

250

251 Moore and Lantos have analyzed high-profile disagreements between families and hospitals and
252 noted that many conflicts begin with a SM post that goes “viral,” sometimes unintentionally on
253 the part of the parents.^{27,28} At least one parent in our study described feeling that her large SM
254 following influenced her daughter’s doctors’ willingness to try interventions identified through
255 SM. More frequently, our participants acknowledged turning to SM to seek encouragement from
256 other parents to “stand their ground” in disagreements with clinicians. Following the
257 recommendations of parents in our study, including the request for further education regarding
258 SM use, might help to prevent some of these situations and to promote a collaborative approach
259 to conflict resolution when disagreements do arise.

260

261 The parents in our study were self-selected and members of our cohort were more likely to be
262 white and educated than the general population; they were also overwhelmingly female, which is
263 unfortunately common in qualitative research in pediatric settings. Online support groups
264 themselves may not be diverse and inclusive communities, and parents of color likely have
265 significantly different experiences with SM and with trust in physicians and medical institutions.
266 Adolescent perspectives were also not explored in our study.^{29,30}

267

268 Parents offered valuable insights regarding their experiences navigating SM, including specific
269 recommendations for how pediatricians might approach discussing parental SM use. Future
270 research will seek to evaluate the utility of these recommendations for practitioners, including
271 the pediatric oncologists whose patients' parents participated in our study.

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LEGENDS

FIGURE 1 How parents use SM affects perceptions of risks and benefits.

FIGURE 2 How parents assess trustworthiness of information on SM and resolve tensions between information on SM and HCP recommendations.

TABLE 1 Characteristics of study participants.

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

TABLE 3 How HCPs respond to social media use.