

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

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

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

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

METHODS

Eligibility criteria and study recruitment

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

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

Data collection

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

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

Data analysis

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

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

RESULTS

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

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

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

Benefits, risks and ethical issues

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

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

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

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

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

Credibility, conflicting information and trust

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

Although parents did raise concerns about misinformation, as above, these complaints were less 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

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

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

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

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

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

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

DISCUSSION

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

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

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.