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Peer reviewed|Thesis/dissertation
Supportive use of social media among parents of childhood cancer survivors

DISSERTATION

submitted in partial satisfaction of the requirements
for the degree of

DOCTOR OF PHILOSOPHY

in Public Health

by

Justin Gregory Wilford

Dissertation Committee:
Professor Lari B. Wenzel, Chair
Associate Professor Dara H. Sorkin
Assistant Professor Suellen Hopfer

2018
DEDICATION

To

Audra, Max, and Maesie

and all families affected by childhood cancer

in recognition of your fierce determination to thrive against the odds
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CURRICULUM VITAE

Justin Gregory Wilford

EDUCATION

Doctor of Philosophy, University of California, Irvine, Program in Public Health, 2018
Doctor of Philosophy, University of California, Los Angeles, Geography, 2010
Master of Arts, Arizona State University, Political Science, 2003
Bachelor of Arts, Arizona State University, Psychology, 2000, Cum Laude

ACADEMIC APPOINTMENTS
(selected)

2017 – 2018   Graduate Teaching Associate, Program in Public Health, UC Irvine
2017 – 2018   Graduate Research Assistant (Dr. Lari Wenzel), Public Health, UC Irvine
2015 – 2018   Graduate Teaching Assistant, Program in Public Health, UC Irvine
2011 – 2017   Visiting Lecturer, Academic Advancement Program, UCLA
2010 – 2014   Visiting Lecturer, Department of Geography, UCLA
2012 – 2014   Research Associate, Center for Religion and Civic Culture, USC

PUBLICATIONS
(selected)

Wilford, J., Buchbinder, D., Fortier, M., Osann, K., Shen, V., Torno, L., Sender, L., Parsons, S., Wenzel, L. 2017. ‘She was a little social butterfly’: A Qualitative Analysis of Parent Perception of Social Functioning in Adolescent and Young Adult Brain Tumor Survivors. Journal of Pediatric Oncology Nursing. 34(4): 239-249.


ABSTRACT OF THE DISSERTATION

Supportive use of social media among parents of childhood cancer survivors

By

Justin Gregory Wilford

Doctor of Philosophy in Public Health

University of California, Irvine, 2018

Professor Lari B. Wenzel, Chair

Childhood cancer survivors (CCS) face a lifetime of significantly elevated risks for chronic and life-threatening illnesses. The unknown challenges of survivorship contribute to elevated levels of emotional distress for parents of CCS. With few clinical supportive resources available, parents of CCS are more frequently turning to online social media for peer support. Because social media have become increasingly important to parents, they represent a critical context in which parents access and share CCS-related support. To date, little research exists on the supportive use of social media among parents of CCS. Thus, an explanatory sequential mixed-methods design was used to (1) examine the relation between social media use of parents (age >18) of young CCS (age <13; >1 year out of treatment), parent social media peer relationships—operationalized as a composite measure, online social integration (OSI)—and parent emotional distress; (2) describe the parent transition into survivorship and identify potential points for social media interventions in that transition; and (3) identify and describe the experiences of seeking, joining, and interacting in cancer-related social media platforms. Quantitative results showed that social media use was positively associated with OSI ($r_s = 0.29; p<0.01$), and also...
positively associated with parent depression when controlling for OSI ($\beta = .28$, $p < 0.01$).

However, bootstrapping mediation analyses provided evidence that OSI competitively mediates the relationship between social media and depression among parents ($c = -.12$, 95% CI -0.03, -0.21) in such a way that it offsets the potentially deleterious relationships between social media use and depression. Qualitative findings first showed that parents experienced the transition off cancer treatment as uniquely distressing and ideal for supportive interventions because it represents a disruption of the hard-won safety represented by regular clinical relationships. Second, parents shared a common process of supportive social media use that culminated in sharing informational, emotional, appraisal, and experiential support with experientially similar parents on disease-specific Facebook groups. The findings from this research provide a foundation for developing and evaluating targeted, low-cost, and exportable social media interventions that improve survivorship outcomes for parents and children affected by cancer.
I. INTRODUCTION

I.1 Background and significance

I.1a Quality of life and health risks among childhood cancer survivors.

Today, over 420,000 childhood cancer survivors (CCS) are alive in the United States, and one in 750 individuals in the United States is a survivor of childhood cancer [1]. Despite these successes, the lifetime disease burden remains inordinately high for CCS [2–4]. Compared to their healthy siblings, it is estimated that CCS have a 15-fold increase in risk for primary and secondary cancers, a 15-fold increase in risk for congestive heart failure, an 11-fold increase in risk for coronary artery disease, a 10-fold increase in risk for stroke, and a 9-fold increase in risk for kidney failure [2]. Compared to the general population, it is estimated that CCS have a 3.5-fold increase in risk for metabolic syndrome [5], 2.4-fold increase in risk for obesity, and up to 13-fold increase in risk for diabetes mellitus [6]. Other significant risks remain for chronic fatigue [7], osteopenia/osteoporosis [8], and early aging [9, 10]. In a recent study of adult survivors of acute lymphoblastic leukemia, 64% of survivors were found to be insulin resistant [4], a significant determinant of many serious chronic illnesses for which CCS are at risk [5, 11]. Recently, it has been estimated that by age 45 the predicted cumulative prevalence among CCS is 95.5% for any chronic health condition, and 80.5% for a life-threatening health condition [12]. The health problems facing CCS are lifelong, increase with age, and can result in early mortality [13].

I.1b Survivorship transition for parents of childhood cancer survivors

Not only are CCS at high risk for acute and chronic disease throughout their lifetimes [2, 14], but reaching common life milestones, such as marriage and career employment, is
significantly more difficult for survivors [15–17]. Thus, it is increasingly recognized that the unique challenges of parenthood in the context of childhood cancer do not dissipate after treatment ends, but rather change in unexpected ways [18–20]. The unknown challenges of survivorship contribute to a common pattern of distress among parents of CCS where distress rises immediately after diagnosis, decreases through treatment and then rises again immediately after treatment ends [21–23]. Even after this post-treatment rise dissipates, parents of CCS report higher levels of distress than their non-cancer counterparts long after treatment ends [24]. As parents move from diagnosis through treatment, from treatment into follow-up care, and from follow-up care into long-term survivorship, they are faced with different challenges in diverse contexts [25–28]. Such challenges may motivate parents to seek supportive resources online, particularly in disease-specific social media groups [29, 30]. To date, the parent experience of seeking supportive resources on social media while progressing through the cancer journey and transitioning between its phases remains understudied.

The period around the end of treatment (EOT) is characterized by parental emotional distress [31–33], even if in the context of other positive emotions [34, 35]. The transition off of treatment and into long-term survivorship marks a dramatic change in the relationship between parents and their child’s clinical care team. The regular routine of treatments and lab appointments abruptly ends, followed by increasingly extended intervals between follow-up appointments that eventually transition into even larger intervals between survivorship clinic appointments.

Much of the focus on parent experience after childhood cancer treatment has been placed on the period immediately after treatment. Studies examining cross-sectional data show that
parent emotional and psychological distress is substantially elevated at EOT and may remain higher than population norms for years afterward [36–38]. However, a longitudinal study by Maurice-Stam and colleagues [31] showed a common trajectory of steady decline in parent distress after transient increase around EOT. Together, these findings suggest a common experiential trajectory among parents of CCS, but the survey data leave its detailed contours unexplored. The subjective experience of this common trajectory may provide important insight for the development and evaluation of late-effect management and preventive health interventions for families of young CCS.

Qualitative studies of the parent experience of EOT have explored parents’ reflections on the transition off treatment and into survivorship in regard to parent self-identity [33], family functioning [34], and shifting emotional experiences [35]. Such studies provide rich and valuable data for understanding the subjectivity of a common experiential trajectory in parenting a young survivor. Rarely examined in these qualitative studies, however, are parents’ perceptions of factors related to potential long-term survivorship health interventions: social media engagement, changing clinical relationships, survivorship information needs, late effect management, and interest in preventive health behaviors. Recent studies have shown parent concerns over these factors evolve from EOT throughout the course of long-term survivorship [18, 19, 39].

1.1c Online supportive care seeking for parents of childhood cancer survivors

For many parents of CCS, survivorship is experienced as a pediatric chronic illness, due to late effects and developmental delays [16, 18, 20, 40, 41]. In this context, low social support is positively associated with parental emotional distress [42–44]. Stressors related to disease management, uncertainty about their child’s future [27, 28], and feelings of social isolation [20,
highlight the importance of supportive social relationships in the context of childhood cancer survivorship. Jackson and colleagues [46] detected a pattern in which parents commonly perceived a high level of social support initially at diagnosis, but reported it rapidly declining after six months and then steadily declining for another two years. Once treatment ends, supportive relationships are experienced as substantially less available than in the first 6 months after diagnosis, yet the period immediately after treatment ends is often experienced as uniquely stressful and requiring additional social support [32, 47].

Few social-relational resources are available for parents of CCS [48]. During treatment, parents are likely to meet other parents in waiting rooms and infusion centers; but once treatment ends, parents have few opportunities to connect with other parents who share the childhood cancer caregiving experience [49]. Thus, many turn to social media—defined as an online network that allows individuals to create personal profiles and communicate with other individuals in that network—for social support [50]. Online support groups for patients and caregivers are almost as old as the internet itself [51], but only in the past decade have social media platforms, such as Facebook, Instagram, and Twitter, emerged as resources for social support among patients and caregivers facing medical challenges [30]. The rise in health-related social media use among parents has coincided with a general rise in social media use. In 2015, the Pew Research Center estimated that 75% of parents in the U.S. used social media regularly, compared to 68% of the general population [52]. More recently, it was estimated that 75% of the general population seeks health information on social media [53]. For parents of children with chronic illnesses, social media platforms such as Facebook have become popular ways to find and connect with other experientially similar parents [54, 55]. In disparate disease contexts, from
congenital anomalies to prenatal care to childhood cancer, evidence suggests that parents are finding each other and creating ad hoc communities through these social media platforms [56–58].

There is insufficient evidence to determine the level and quality of social relationships provided on these platforms for parents in any particular disease context. However, observational studies have detected a strong, positive relationship between social media use and emotional distress that has come to be known as “Facebook depression” [59]. While it is unclear to what extent emotional distress drives social media use or social media use increases emotional distress, the relationship between social media use and emotional distress appears to be robust [60–62]. Mechanisms have been proposed for either directional relationship: depression may drive social media use through an increase in support seeking [63, 64], but social media may also cause emotional distress through negative self-comparisons from displays of higher status [62] and the opportunity cost of developing off-line relationships [62].

Alternatively, large cross-sectional studies of adult social media users in the U.S. indicate that greater social media usage is related to greater tie-strength with others, independent of offline interactions [65], and supportive interactions over social media are associated with an increase in positive affect over time [66]. In a smaller cross-sectional study of an online cancer support group, researchers found that greater interaction in the online group was associated with greater social support and psychosocial health [67]. Another study of a rare disease social media support group found that urban/rural disparities in social support, due to fewer peer support opportunities in rural environments, were mitigated through online interaction [68].
The role of social support on social media for parents of childhood cancer survivors

While little is known about parents of CCS seeking peer relationships on social media, qualitative studies have shown that parents report receiving and providing several different types of social resources, with emotional and informational social support being the most common [50, 69]. A substantial gap remains in our understanding of how social relationships developed through social media are related to important outcomes such as parent psychosocial health.

One potential social media mechanism for producing beneficial psychosocial outcomes is homophilic peer support [69, 71, 83]. Homophily is the sociological phenomenon whereby similar individuals are more likely to have strong social ties than dissimilar individuals [70]. The potential for social media to provide a platform for disease-specific homophilic sorting is now widely recognized [71–73]. Disease-specific communities of experiential similar peers on social media have garnered increased attention as researchers have tracked the growth [72], structure [74], and participant experiences [69, 75] in social media groups. Yan and colleagues showed that in large health-related social media groups, experientially similar patients seek each other and develop networks of support based on first-hand disease experience [76]. In a review of internet-based peer support for parents, Niela-Vilén and colleagues [29] concluded that membership in a community of experientially similar peers was an important motivator and outcome for parents seeking support online. Gage-Bouchard and colleagues [69] analyzed one year of communication between parents in a Facebook group for parents of pediatric leukemia patients and found that parents received unique informational and emotional support from experientially similar parents. Additionally, parents seek experientially similar parents for
support off-line as well [77], and the impact of social support may be moderated by the level of experiential similarity between parents [43].

The social-supportive benefits of social media do not appear to be unique. Rather, social media may more readily generate and diffuse these social benefits. Informational and emotional support have long been recognized as off-line communicative resources shared face-to-face [85]. This is also true for the narrower types of social support that emerge from experientially similar peers seeking and interacting with one another [82]. Peer support is the broadest conceptual articulation of such support in the literature on social support among experientially similar individuals, but “experiential support” and “appraisal support” have also been articulated as concepts capturing unique features of peer support [81].

Experiential support has been used to refer to a distinct type of social support that is produced in relationships between individuals who have experienced or are experiencing similar health conditions and treatments [78, 79]. Snyder and Pearse [78] describe the unique benefits of this type of support as the procurement of “first-hand information, insight and even hope” that results in a “comfort and reassurance” between individuals who share the experience of a traumatic health condition or event. Suitor [83], drawing on previous empirical work on social networks and sociological theory, showed that individuals are more likely to benefit from the support of experientially similar others, and that this support comes from the unique “empathetic understanding” and social acceptance of distress that experiential similar individuals share. This empathetic understanding and social acceptance can also be understood through the psychosocial concept of belongingness, most notably elaborated by Baumeister and Leary [80] as a fundamental human motivation. They argue that this motivation can be inferred as fundamental
by observing the remarkable ease by which group belongingness is generated, especially in the context of adverse circumstances, the clear biological harm resulting from social isolation, and the positive neuro-cognitive association between primate brain size and social group size.

In the context of serious health conditions and traumatic events, social belongingness in natural networks of family and friends can be threatened by experiential dissimilarity. As Thoits [81] explains, this natural network of significant others, which she terms the “primary group,” is often disrupted and fails to offer adequate support in the context of a health crisis for at least two reasons. First, significant others are upset at this crisis for sympathetic (desire for their loved one to return to normal health) and selfish (desire for their own lives to return to normal) reasons; thus, the informational and emotional support they offer can be focused on resolving the health crisis as quickly as possible. Second, significant others often have no first-hand experience in the health crisis their loved one is experiencing. Thus, the informational and emotional support is likely to be inadequate or irrelevant to the situation. The potentially ineffective and inappropriate emotional and informational support offered by significant others in a health crisis do not only cause a deficit in support for the affected individual, but they also cause a disruption in their sense of social belonging. In other words, they are no longer understood by their most significant others.

Thus, experiential support, as a distinct type of social support, is an important social resource within the context of health crises or serious chronic health conditions. The term experiential support is often used interchangeably with the broader concept of “peer support,” which is defined by Dennis [82] as “the provision of emotional, appraisal and informational assistance by a created social network member who possesses experiential knowledge of a
specific behaviour or stressor and similar characteristics as the target population.” This definition indicates that peer support, as a distinct construct, is best considered as a method rather than a resource. As a method, peer support refers to the type of relationship that generates particular types of supportive resources: “emotional, appraisal, and informational,” in the definition of Dennis [82]. Experiential support, however, is a particular type of supportive resource that is generated among experientially similar peers. It refers primarily to the sense of belongingness that emerges from the communication between experientially similar individuals, particularly when the shared experience is traumatic [78, 83].

Appraisal support is a second type of social support that is generated by peer interaction. The concept was originally articulated as an influential mechanism in the transactional model of stress in which an individual’s appraisal of a stressor and the self’s resources for coping with that stressor produces corresponding levels of psychological and emotional stress [84–86]. In the context of peer support, Dennis [82] and Thoits [81] articulated appraisal support as a more general communicative resource that allows individuals to evaluate and regulate their thoughts, emotions, and behaviors in the specific and unique context of a disruptive health crisis. Going beyond the transactional model of stress, this broader self-evaluative concept articulates appraisal support not only as a resource for evaluating stressors and coping abilities, but also for evaluating and regulating the context-appropriateness of one’s emotions, thoughts, and behaviors. Among experientially similar peers, such appraisal support is communicated in a variety of ways from verbal affirmation (“It’s normal to feel that way”) to non-verbal cues (How are experientially similar peers talking and acting in relation to similar events?).
Because social media affords the creation of private disease-specific groups alongside easy homophilic sorting on a wide scale, these peer-supportive resources may be particularly salient in the context of parents seeking support online. Despite this, little is know about how parents are seeking, engaging in, and sharing social support on disease specific social media groups. Understanding such online behaviors will allow for more meaningful and effective social media interventions for parents of CCS.

I.2 Public health relevance

Parents represent an important yet untapped and understudied resource to improve poor QoL and increased health risks in CCS. Parents in the general population play an outsized function in determining QoL and long-term health of their children [129]. Yet parents of CCS often experience the transition into survivorship as emotionally distressful. Potentially potent targets for parent interventions that may not only improve parent distress but also improve outcomes for CCS are the social media platforms that parents of CCS are already using. Recent evidence shows that online social networks may have significant disease-management and health behavior modifying effects on social media members [30-33]. Such research suggests that the ways members use social media, and the specific characteristics of these platforms may influence the spread of health-promoting information and behaviors among members. However, little is known about the use and perceptions of social media by parents of CCS. Because social media represent a key intervention tool for improving parent psychosocial health, screening adherence, disease management, and related preventive health behaviors, these gaps in knowledge are a
significant barrier to the design and evaluation of social media interventions for early 
survivorship health promotion.

I.3 Aims

This mixed-methods study was designed to achieve three primary aims: The first primary 
aim was to examine parent social media use levels, parent social relationships on social media, 
and parent emotional distress. Our sub-aims were to first describe the use and peer relationship 
characteristics on social media among parents of CCS. Our second sub-aim was to examine the 
relationship between social media use levels and parent emotional distress. In our third sub-aim, 
we examined the role of parent social media peer relationships—operationalized through a 
composite measure we term online social integration (OSI)— in the association between parent 
social media use and emotional distress.

The second primary aim of this study was to investigate survivorship experiences of 
parents of CCS in order to illuminate inflection points in the cancer journey in which supportive 
needs are most salient and social media interventions potentially most appropriate. In order to 
accomplish this aim, we analyzed in-depth interviews with parents of CCS and produced a 
grounded-theoretical model of a common experiential trajectory into long-term survivorship for 
parents of CCS.

The third primary aim of this study was to examine the social-supportive perceptions and 
experiences of parents of CCS in the context of social media. Through in-depth interviews, 
parents were asked about their initial engagement with social media for support related to 
childhood cancer, the supportive interactions they experienced on social media, and memorable
positive and negative experiences on social media. The qualitative data produced by these interviews was thematically analyzed and used to produce a theoretical model of supportive social media use.
II. METHODS

II.1 Participants and procedures

Participants in the study were English-speaking parents of young CCS who were members of two large social media childhood cancer support groups run by two nonprofit organizations, MaxLove Project and Momcology. MaxLove Project is a California-based non-profit that focuses on health behavior education to improve quality of life in childhood cancer survivors; Momcology is a Minnesota-based non-profit that focuses on providing social support for parents of children affected by cancer. Eligibility criteria for participation were 1) parent of a survivor of pediatric solid tumor or blood cancer; 2) at least 18 years of age; 3) child is at least one year off of treatment; and 4) child is currently under 13 years old. The rationale for the inclusion criteria was driven by the aim to target parents who were likely to have a high degree of influence over their children’s health behaviors. Parents were recruited through posts to each organization’s social media parent support group. The posts were disseminated once a week for three weeks. The IRB-approved recruitment messages provided parents with a description of the study and a URL for a web-based survey that began by assessing eligibility and eliciting informed consent. The online survey used REDCap software designed by Vanderbilt University and administered by the University of California, Irvine. All surveys were completed in June and July of 2017.

In the survey, parents were asked if they would be willing to participate in a telephone interview. Parents who agreed were purposively sampled to achieve adequate representation in
self-reporting of ethnicity, education level, cancer type, and social media use. All interviews were conducted by the author who is trained in qualitative interview techniques.

II.2 Measures

All survey measures are available in Appendix A. A summary of survey measures can be found in Table 2.1. The semi-structured interview guide is available in Appendix B.

Table 2.1. Summary of survey measures

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<th>Measure</th>
<th>Description</th>
<th># items</th>
<th>Citations</th>
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<tr>
<td>Survivorship Health Awareness</td>
<td>Measures parent awareness of survivorship health risks (1, 9-18) and preventive health behaviors (2-8).</td>
<td>18</td>
<td>Chervan et al. (2014); Landier (2015)</td>
</tr>
<tr>
<td>Online social relationships</td>
<td>Measures parents use/behavior on social media (1-36) and online relationship characteristics (37-66)</td>
<td>66</td>
<td>Valente (2010)</td>
</tr>
<tr>
<td>Social Support Received (online)</td>
<td>Measures positive and negative social exchange</td>
<td>16</td>
<td>Newsom et al (2005)</td>
</tr>
<tr>
<td>Social Support Perceived (online)</td>
<td>PROMIS short forms adapted for social media social support</td>
<td>12</td>
<td>Hahn et al. (2010; 2014)</td>
</tr>
<tr>
<td>Social Support Perceived (offline)</td>
<td>NIH PROMIS short forms for adult Emotional and Informational Support, and Social Isolation</td>
<td>12</td>
<td>Hahn et al. (2010; 2014)</td>
</tr>
<tr>
<td>Depression</td>
<td>NIH PROMIS Adult Depression Short Form</td>
<td>4</td>
<td>Riley et al. (2011); Pilkonis (2014)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>NIH PROMIS Adult Anxiety Short Form</td>
<td>4</td>
<td>Riley et al. (2011); Teresi et al (2016)</td>
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Demographics, disease, and treatment. The online survey included the following items to assess parent demographics: age, gender, education level, marital status, and ethnicity/race.

The survey also collected information on child’s diagnosis, treatments received, and time off treatment.

Parent social media use. Parent social media use was assessed using a question matrix with the lead prompt and question: “Social media are websites or apps that allow users to create
personal profiles and share information. Examples are Facebook, Twitter, Instagram, and Google+. On social media, how often do you...” It was followed by a matrix of 4 fields that could be answered on a Likert-type scale from “Never” to “Several times a day.” The fields were “Respond to a post by liking, loving, etc.,” “Post a message,” and “Comment on a post,” “Send/receive a direct message.” All four responses were added to create a social media use index. Complete case analysis ensured that index scores were only created for participants who answered all four fields in the matrix.

**Parent Online Social Integration.** Parent online social integration (OSI) was assessed as a composite of four measures, three of which were modified instruments originally developed by the Patient-Reported Outcomes Measurement Information System (PROMIS). PROMIS instruments have been developed through a National Institutes of Health sponsored cooperative research program that aims to develop, evaluate, and standardize item banks that measure patient-reported outcomes across different disease contexts in the U.S. population [87]. Three PROMIS instruments—Emotional Support Short Form 4a, Informational Support Short Form 4a, and Social Isolation Short Form 4a—were modified by adding “on social media” to each item. For example, for social isolation, the first item in the short form in the unmodified version reads “I feel left out...” with Likert-type answer scale from “Never” to “Always.” The modified version reads: “On social media I feel left out...” The fourth measure, an indicator of online peer network size, was the number of CCS parent-friends developed online. To account for known social-relational covariates of psychosocial health, we created an online social integration index (OSI) by creating standardized scores of each of the four sub-scales, adding online emotional support (OSI – Emotional), online informational support (OSI – Informational), and online peer
network size (OSI – Network Size) and subtracting online social isolation (OSI – Isolation). Social isolation has been shown to be positively associated with emotional distress [88] [89] [90], while emotional and informational support and network size have been shown to be negatively associated with emotional distress [81, 91, 92]. Complete case analysis ensured that index scores were only created for parents who completed all of the questions in the OSI subscales.

**Parent Depression and Anxiety.** Parent depression and Anxiety were measured using PROMIS Adult Depression Short Form 4a and Adult Anxiety Short Form 4a. Both scales have been validated against legacy instruments and through observational research [93–95]. Furthermore, the 4-item short forms are an excellent compromise between ensuring construct validity and minimizing participant burden, as correlations of the 4-item short forms for depression and anxiety with the full item bank are above 0.9 [96]. Clinically relevant levels of PROMIS measures are considered to be 0.5 SD above the population mean (anchored at a T-score of 50), represented by a score of 55 or higher [97].

The semi-structured interviews followed an interview guide consisting of open-ended questions focused on three broad themes: clinical follow-up care and survivorship resources, preventive health behavior resources and information, and post-treatment online survivorship support. Table 2.2 presents survivorship-care-related questions. Probing follow-up questions were asked for clarification or elaboration. All interviews were audio-recorded and transcribed verbatim.
II.3 Quantitative analysis

Demographic and disease- and treatment-related characteristics were summarized using descriptive statistics. Analysis was conducted to detect if response data were missing completely at random (MCAR). If data were MCAR then the remaining completed responses would be a random sample of the larger study sample, and complete case analysis would be appropriate [43]. Randomness of cases with missing data was examined by testing for independence (using Fisher’s Exact Test) between cases with missing data and cases with complete data on ethnicity, marital status, education, and age.

Due to the non-normal distribution of some of the variables, bivariate correlations between demographic and disease-related characteristics, social media use, OSI, depression, and

---

**Table 2.2. Survivorship-related interview questions**

1. **How are you and your survivor doing right now?**
   
   Follow-up prompts: What was treatment like for you, your family, and child? What was it like to end treatment? How well do you think the doctors and healthcare team did a good job transitioning you and your child into survivorship?

2. **Can you recall being counseled on survivorship (late effects, follow-up care, long-term risks, continuing challenges) by your healthcare team?**
   
   Follow-up prompts: Can you tell me who counseled you and what it was like? Did you find it helpful? Were you given any survivorship-related materials or resources?

3. **Are you aware of any survivorship-related programs offered by your hospital or healthcare provider. Have you been involved in any of these programs?**
   
   Follow-up prompts: How do you feel about the survivorship-related programs and resources that are available? Does your spouse feel differently? What do you wish your hospital had for survivors that they don’t now?

4. **Have you looked for any survivorship resources online? Social media? Apps? What do you wish was available online/mobile apps?**
anxiety were assessed using Spearman’s Rho. Multiple regression models were used to analyze associations between social media use and OSI as independent variables and parent depression and anxiety as dependent variables. Parent age and education were included as covariates because preliminary correlational analysis indicated associations between them and OSI variables. Mediation analysis was conducted in order to identify the relationship between social media, OSI, and parent depression and anxiety. Bootstrapping procedures for mediation were used in order to estimate a robust confidence interval (CI) of the indirect effect of a mediator variable (in this case, OSI). Bootstrapping procedures outlined by Preacher and Hayes [44] were followed. Bootstrapping in statistics is the repeated random selection of new samples from an original sample in order to produce multiple estimates of a parameter. The Preacher and Hayes’s bootstrapping procedure, which has been well-validated, allows for non-normal distributions and smaller sample sizes, and is now the preferred method for estimating indirect effects [44, 45]. Each bootstrapping model used 5,000 iterations. Stata 14.2 (College Station, TX) was used for all descriptive and inferential analyses.

II.4 Qualitative analysis

Transcribed interviews were analyzed using an inductive grounded theory approach [98]. According to this approach, data coding and theory selection inform each other in a multi-stage iterative process. An initial round of coding was completed in Atlas.ti on the entire sample to generate all possible inductive codes. Memos and summaries were generated alongside this initial coding and used to achieve consensus on naming and meaning of themes. A second round of coding on the full sample was conducted by grouping the most salient codes under the
identified emergent themes. Codes, grouped by broader themes, were then used in the Atlas.ti Document Table function to produce a matrix by which case data could be compared to each other by code in a constant comparison analysis [99]. The grounded theory approach allows for key themes to emerge during the coding, memo-writing, and discussion process, and used to produce theoretical elements that can be compared back to coded data. A full theoretical model emerges from this iterative process. To check for coding and thematic validity, the author and three parent participants reviewed the thematically organized and de-identified raw data alongside the emergent theoretical model. Suggested edits were made and resubmitted to authors and participants until consensus on coding and theory building was reached.
III. QUANTITATIVE RESULTS

III.1 Participant Characteristics: Survey

A total of 135 social media support group members responded to the online survey link in the recruitment message, and of these, 112 confirmed eligibility, provided informed consent, and completed the survey. The primary variables included in these analysis are composed of 24 survey questions that obtained a complete response rate by 80.4% of respondents. Tests for independence demonstrated that data were MCAR. Parent demographic and child disease- and treatment-related characteristics are presented in Table 3.1. The majority of parent participants were mothers (94%), non-Hispanic white (74%), highly educated (64% reported holding a college degree or higher), and married (86%).

III.2 Social Media Support Seeking

On average parents reported spending 20.2 hours online per week (SD = 16.4), ranging from 2 to 100 hours. Parent age, education, ethnicity, marital status, and child diagnosis were not associated with time spent online. Parents reported spending an average of 47.3% of their time online on childhood cancer websites, social media pages and groups, or in childhood-cancer-related communication. As illustrated in Figure 3.1, parents who reported spending time online above the sample median (15 hours), averaged over 20 more hours per week online than parents below the sample median. Although parents above the median reported a lower percentage of online time spent on childhood-cancer-related activities than parents below the median (42.7% vs. 52.1%), their total time spent on online childhood-cancer-related activities was significantly higher (13.5 vs. 5.5, \( p < 0.00 \)).
Of the various resources available online, parents used childhood-cancer-related social media most frequently. As illustrated in Figure 3.2, 65.6% of parents report using a childhood-cancer-related social media platform once a day or more. In comparison, the next most-frequently used online resources is the Google search engine, which 27.8% of parents report using for childhood-cancer-related purposes once a day or more. Hospital websites and medical information websites like WebMD were either never used or are not currently used by 74.2% and 62.9% of parents, respectively. Parent age, education, ethnicity, marital status, and child diagnosis were not associated with frequency of childhood-cancer-related social media use.

Parents reported using Facebook far more frequently than other social media platforms. As shown in Fig. 3.3, 80.6% of parents reported using Facebook at least once a week, with 60.2% reporting daily use. The next most frequently used social media platform was Instagram followed by Pinterest, with 29.3% and 16.2% reporting at least weekly use, respectively. 99% of parents reported having met another childhood cancer parent through Facebook. The next highest-endorsed platform for meeting another childhood cancer parent was Caringbridge (29.9%) followed by Instagram (27.6%). A strong majority of parents (82.7%) endorsed Facebook as a “good” or “extremely good” platform for “sharing and receiving reliable and high quality information on diet, physical activity, and other healthy behaviors.” The next highest-endorsed

![Fig. 3.1 Parent-reported hours spent online](image)
Table 3.1. Parent demographics and child’s clinical characteristics, total surveyed and interviewed

<table>
<thead>
<tr>
<th>Variable</th>
<th>Total Parents (n = 112)</th>
<th>Total Children (n = 20)</th>
<th>Parents Interviewed</th>
<th>Children of Parents Interviewed</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age: mean (SD)</strong></td>
<td>38.8 (6.5)</td>
<td>7.8 (3.1)</td>
<td>38.7 (6.7)</td>
<td>8.2 (2.4)</td>
</tr>
<tr>
<td><strong>Gender (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>105 (94%)</td>
<td>17 (85%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>7 (6%)</td>
<td>3 (15%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Ethnicity (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-Hispanic white</td>
<td>83 (74%)</td>
<td>15 (75%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-Hispanic black</td>
<td>2 (2%)</td>
<td>0 (0%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>12 (11%)</td>
<td>1 (5%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asian/Pacific Islander</td>
<td>6 (5%)</td>
<td>1 (5%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>8 (7%)</td>
<td>3 (15%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Diagnosis (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brain tumor</td>
<td>29 (27%)</td>
<td>3 (15%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Leukemia</td>
<td>42 (39%)</td>
<td>9 (45%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-Hodgkin’s</td>
<td>4 (4%)</td>
<td>2 (10%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neuroblastoma</td>
<td>8 (7%)</td>
<td>2 (10%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sarcoma</td>
<td>12 (11%)</td>
<td>3 (15%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ovarian Germ Cell</td>
<td>10 (9%)</td>
<td>1 (5%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>7 (6%)</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Treatments Received (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surgery (brain)</td>
<td>23 (21%)</td>
<td>3 (15%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Radiation</td>
<td>41 (37%)</td>
<td>7 (35%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>106 (95%)</td>
<td>19 (95%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Time off treatment (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between 1 and 2 years</td>
<td>53 (48%)</td>
<td>8 (40%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between 2 and 5 years</td>
<td>49 (45%)</td>
<td>9 (45%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between 5 and 10 years</td>
<td>8 (7%)</td>
<td>3 (15%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Marriage Status (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>95 (86%)</td>
<td>15 (75%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Separated</td>
<td>9 (8%)</td>
<td>2 (10%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Divorced</td>
<td>6 (5%)</td>
<td>3 (15%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; High school diploma</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school diploma</td>
<td>7 (6%)</td>
<td>1 (5%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some College</td>
<td>32 (29%)</td>
<td>6 (30%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>College degree</td>
<td>71 (64%)</td>
<td>13 (65%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
platform for sharing preventive health information was Caringbridge (32.9%), followed by Instagram (19.8%).

As illustrated in Figure 3.4, parents reported greatest social media use frequency in responding to others’ posts with emojis (“like,” “love,” etc.) (89% report responding at least once a week) and the least frequency in publishing original posts of their own (63.6% report publishing a post at least once a week). Parents also reported commenting on posts more frequently than writing original posts (77.8% vs. 63.6% at least once a week).

Most parents reported developing close relationships with other childhood cancer parents through social media. As illustrated in Fig. 3.5, 87.6% of parents report developing a close relationship with at least one other parent; nearly half report close relationships with at seven other childhood cancer parents developed through social media. Parent age, education, ethnicity, and marital status were not associated with frequency of childhood-cancer-related social media use. However, parents of leukemia survivors had significantly higher odds of having developed seven or more close relationships with childhood cancer parents through social media (OR=2.4; CI 1.04-5.6).

III.3 Parent Online Social Integration

The mean OSI-Emotional and the OSI-Informational raw scores were 15.6 and 14.9, respectively, out of a possible range of 4 to 20, with higher scores indicating better online support. The mean OSI-Social Isolation raw score was 8.7 out of a possible range of 4 to 20, with higher scores indicating more social isolation. The mean number of CCS parent-friends developed through social media (OSI-Network Size) was 4.6. The highest rated item among the
Figure 3.2. Parent reported frequency of childhood-cancer-related online activity

- **Never or not currently**
- **At least once a week**
- **Once a day or more**

<table>
<thead>
<tr>
<th>Activity</th>
<th>Never or not currently</th>
<th>At least once a week</th>
<th>Once a day or more</th>
</tr>
</thead>
<tbody>
<tr>
<td>Use social media</td>
<td>10.4%</td>
<td>65.6%</td>
<td>24.0%</td>
</tr>
<tr>
<td>Use Google search engine</td>
<td>24.0%</td>
<td>32.0%</td>
<td>40.2%</td>
</tr>
<tr>
<td>Use a hospital's website</td>
<td>18.6%</td>
<td>74.2%</td>
<td>7.2%</td>
</tr>
<tr>
<td>Use a WebMD-like website</td>
<td>26.8%</td>
<td>62.9%</td>
<td>10.3%</td>
</tr>
<tr>
<td>Use another website</td>
<td>28.4%</td>
<td>51.6%</td>
<td>20.0%</td>
</tr>
</tbody>
</table>
Figure 3.3. Parent perceptions of childhood-cancer-related utility of social media platforms

<table>
<thead>
<tr>
<th>Platform</th>
<th>Use at least once a week</th>
<th>Met another childhood cancer parent through platform</th>
<th>Good for sharing and receiving preventive health information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caringbridge</td>
<td>6.1%</td>
<td>29.9%</td>
<td>32.9%</td>
</tr>
<tr>
<td>Facebook</td>
<td></td>
<td></td>
<td>80.6%</td>
</tr>
<tr>
<td>Google+</td>
<td>9.2%</td>
<td></td>
<td>7.2%</td>
</tr>
<tr>
<td>Instagram</td>
<td></td>
<td></td>
<td>29.3%</td>
</tr>
<tr>
<td>Inspire</td>
<td>2.0%</td>
<td>0.0%</td>
<td>2.0%</td>
</tr>
<tr>
<td>Pinterest</td>
<td>6.2%</td>
<td>7.1%</td>
<td>3.1%</td>
</tr>
<tr>
<td>Twitter</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
OSI sub-scale measures was in response to the prompt: “I have people on social media who will listen to me when I need to talk about my child-survivor...” to which 81.5% of parents responded either “usually” or “always.” The lowest rated item among the OSI subscale measures was in response to the prompt: “On social media, I feel left out...” to which 3.2% responded either “usually” or “always.”

### III.4 Parent anxiety and depression

Mean depression T-score was 53.4 (SD=9.9) and mean anxiety T-score was 63.8 (SD=6.8). The proportion of parents who reported clinically relevant levels of depression and anxiety (i.e., a T-score above 55) was 51% and 91% respectively. Eight percent of parents
reported scores for depression, and 23% reported scores for anxiety, in the severe range. Parent depression and anxiety were not associated with demographic variables such as parent age, child age, parent education level, or marital status.

III.5 Correlational and Mediation Analyses

In bivariate correlational analysis, shown in Table 3.2, social media use was positively associated with OSI ($r_s = 0.36; p<0.01$), but was marginally significant at the 0.05 level for depression ($r_s = 0.19, p=0.058$) but not anxiety ($r_s = 0.18, p=0.08$). However, OSI was negatively associated with depression ($r_s = -0.23; p < 0.05$) and anxiety ($r_s = -0.20; p < 0.05$) in bivariate analysis. In a multivariate regression model that includes OSI as a covariate of depression and anxiety, the association between social media use and depression becomes significant ($\beta = .28, p < 0.01$) but does not reach significance at the 0.05 level for anxiety ($\beta = .19, p = 0.08$).

In order to determine whether OSI mediates the relationship between social media use and parent depression, bootstrapping analyses were conducted on depression and anxiety separately. The five relationships that are examined in mediation analysis are presented in Table 3.3, and the mediation model with paths $a$, $b$, and $c'$ are presented in Figure 3.5. The direct effect of social media use ($c'$) indicates the unit change in depression or anxiety for every unit increase in parents’ social media use index score, controlling for OSI. The indirect effect ($c-c'$) is the total

![Fig. 3.5. Number of close relationships with other childhood cancer parents developed through social media](image-url)
Table 3.2 Online social integration and emotional distress means, standard deviations, and correlations

<table>
<thead>
<tr>
<th></th>
<th>M</th>
<th>SD</th>
<th>PROMIS Dep - 4a</th>
<th>PROMIS Anx - 4a</th>
<th>OSI - Emo</th>
<th>OSI - Info</th>
<th>OSI - Iso</th>
<th>OSI-Net Size</th>
<th>OSI Comp</th>
<th>SM index</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression (T-score)</td>
<td>53.4</td>
<td>9.8</td>
<td>0.93</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety (T-score)</td>
<td>63.8</td>
<td>6.8</td>
<td>0.74**</td>
<td>0.93</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>OSI - Emotional</td>
<td>15.6</td>
<td>4.1</td>
<td>-0.27**</td>
<td>-0.11</td>
<td>0.92</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>OSI - Informational</td>
<td>14.9</td>
<td>4.0</td>
<td>-0.23*</td>
<td>-0.10</td>
<td>0.85**</td>
<td>0.93</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>OSI - Isolation</td>
<td>8.7</td>
<td>2.8</td>
<td>0.37**</td>
<td>0.3</td>
<td>-0.37**</td>
<td>-0.31**</td>
<td>0.80</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>OSI - Network size</td>
<td>4.6</td>
<td>2.7</td>
<td>-0.01</td>
<td>-0.10</td>
<td>0.37**</td>
<td>0.34**</td>
<td>-0.28</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>OSI Composite</td>
<td>——b</td>
<td>——</td>
<td>-0.23*</td>
<td>-0.20*</td>
<td>0.71**</td>
<td>0.79**</td>
<td>-0.60**</td>
<td>0.41**</td>
<td>0.91</td>
<td></td>
</tr>
<tr>
<td>SM index</td>
<td>13.9</td>
<td>4.6</td>
<td>0.19</td>
<td>0.18</td>
<td>0.34**</td>
<td>0.26**</td>
<td>0.07</td>
<td>0.36**</td>
<td>0.36**</td>
<td>0.87</td>
</tr>
</tbody>
</table>

Note. PROMIS Dep - 4a, Patient-Reported Outcome Measurement Information System - Depression Short Form 4a; PROMIS Anx - 4a, Patient-Reported Outcome Measurement Information System - Anxiety Short Form 4a; OSI - Emotional, Perceived Online Emotional Support; OSI - Informational, Perceived Online Informational Support; OSI - Isolation, Perceived Online Social Isolation; OSI - Network Size, Number of important childhood cancer parent relationships developed on social media; SM Index, Social Media Index.

a All composite correlations with OSI subscales are calculated with related sub scale removed from composite score.
b Composite score was sum of standardized z-scores of OSI-Emo, OSI-Info, and OSI-Network size minus standardized OSI-Isol and thus had a mean of near zero.

Spearman correlations; * denotes p < 0.05; ** denotes p < 0.01. Cronbach’s Alpha values are listed on the diagonal, except for OSI-Network size, which was composed of only one item.
Table 3.3: Mediation model—bootstrap results to test significant of main and indirect effects

<table>
<thead>
<tr>
<th></th>
<th>$\beta$</th>
<th>SE</th>
<th>Lower</th>
<th>Upper</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Depression</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$a$ Social media use→online social integration</td>
<td>0.36</td>
<td>0.1</td>
<td>0.17</td>
<td>0.56</td>
<td>0</td>
</tr>
<tr>
<td>$b$ Online social integration→depression</td>
<td>-0.33</td>
<td>0.1</td>
<td>-0.54</td>
<td>-0.13</td>
<td>0</td>
</tr>
<tr>
<td>$c$ Total effect: social media use→depression</td>
<td>0.16</td>
<td>0.1</td>
<td>-0.03</td>
<td>0.36</td>
<td>0.11</td>
</tr>
<tr>
<td>$c'$ Direct effect: social media use→depression</td>
<td>0.28</td>
<td>0.1</td>
<td>0.07</td>
<td>0.49</td>
<td>0</td>
</tr>
<tr>
<td>$c-c'$ Indirect effect: social media use→depression</td>
<td>-0.12</td>
<td>0.05</td>
<td>-0.21</td>
<td>-0.03</td>
<td>0.02</td>
</tr>
<tr>
<td><strong>Anxiety</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$a$ Social media use→online social integration</td>
<td>0.36</td>
<td>0.1</td>
<td>0.17</td>
<td>0.56</td>
<td>0</td>
</tr>
<tr>
<td>$b$ Online social integration→anxiety</td>
<td>-0.25</td>
<td>0.11</td>
<td>-0.47</td>
<td>-0.04</td>
<td>0.02</td>
</tr>
<tr>
<td>$c$ Total effect: social media use→anxiety</td>
<td>0.1</td>
<td>0.12</td>
<td>-0.11</td>
<td>0.3</td>
<td>0.35</td>
</tr>
<tr>
<td>$c'$ Direct effect: social media use→anxiety</td>
<td>0.19</td>
<td>0.11</td>
<td>-0.03</td>
<td>0.41</td>
<td>0.08</td>
</tr>
<tr>
<td>$c-c'$ Indirect effect: social media use→anxiety</td>
<td>-0.09</td>
<td>0.04</td>
<td>-0.17</td>
<td>-0.01</td>
<td>0.05</td>
</tr>
</tbody>
</table>

(combined) effect ($c$) of social media and OSI on depression or anxiety, subtracted from the direct (isolated) effect of social media on depression or anxiety. Therefore, the indirect effect indicates the unit change in depression or anxiety attributed to social media use, given the tendency for social media to be strongly associated with OSI.

As illustrated in Fig. 3.6, the mediation model for depression showed significant associations for mediator pathways $a$ and $b$, as well as for the direct effect pathway $c'$. The bias-corrected bootstrap 95% CI for the indirect effect, represented in Fig. 3.6 in parentheses, was significant as it did not cross zero (95% CI = [-0.21, -0.03]). Therefore, the relationship between
social media use and depression is partially mediated by OSI. Because the product of the coefficients of the $a$, $b$, and $c'$ paths is negative (0.36 x -0.33 x .28), the mediation relationship is considered to be competitive [100]. That is, the combined effect of the mediated paths $a$ (social media use on OSI) and $b$ (OSI on depression) is competing with the opposite effect of the direct path $c'$ (social media use on depression). The mediation model of anxiety, also illustrated in Fig. 3.6, showed similar trends but while the indirect effect was significant at the 0.05 level, the direct effect of social media use on anxiety was only significant at the 0.10 level.

![Diagram](image)

**Figure 3.6. Mediation model results: depression and anxiety.** Among parents of young childhood cancer survivors, online social integration partially mediated the relationship between level of social media use and depression. Online social support does not mediate the relationship between social media use and anxiety at the 0.05 level. *denotes p < 0.05; **denotes p < 0.01.
IV. QUALITATIVE RESULTS 1: TRANSITION TO SURVIVORSHIP

IV.1 On-treatment parent experiences

All parents in the sample recalled their child’s treatment as a difficult and challenging experience. In response to the open-ended question, “What was treatment like for you, your family, and your child?”, parents recounted child emotional distress, sibling emotional distress, and parent physical and emotional distress. “We were a mess” (ID 1, father, leukemia) one parent recounted, referring to the entire family unit. Although the physical demands on parents, such as lack of sleep, eased over the course of treatment, parents’ emotional distress continued as they reported coping with difficult side-effects of their child’s treatment, a loss of peer connection for their child during treatment, and adjusting to significant changes in daily lifestyle in the case of a medullablastoma patient who lost significant motor functioning, two central nervous system tumor patients who each lost an eye, and two sarcoma patients who experienced long-term endocrine dysfunction.

Because of the physical and emotional distress surrounding treatment, parents commonly recalled looking forward to EOT: “It’s a sense of relief” (ID 4, mother, glioma), “excitement we thought we were going to feel” (ID 11, mother, leukemia), “a joyous ... occasion” (ID 13, mother, leukemia), “all of the sudden having more time” (ID 17, mother, leukemia). These expectations, parents recounted, were unfulfilled, and upon reflection they commonly looked back on treatment as a time of safety and security that they did not recognize as such at the time. Regardless of how difficult treatment was, and how anticipated was its end, from the vantage
point of being off treatment, those difficult days of treatment were remembered as safe and secure.

IV.2 End-of-treatment parent experiences

Despite the perceived difficulties of the treatment period, the juxtaposition of the “safety” and “security” of regular clinic visits, lab testing, and personal contact with physicians and nurses heightened parents’ sense of absence when treatment ended. Some parents experienced EOT as even more difficult than treatment itself:

“One of the hardest parts of this whole thing was the end of treatment. . . . You felt like you were supported by a bunch of doctors . . . then suddenly it's like you're dropped off a cliff or at least that's the way we felt. [The transition off treatment] was as tough a year as the year of chemo, maybe even harder, because you know you just feel like you're out there on your own.” (ID 15, mother, sarcoma)

“[End of treatment] was very scary for me because I wanted her to be a survivor. I tried for my own stress to calm down but I think my level of stress actually got worse.” (ID 11, mother, leukemia)

Other parents experienced EOT as bringing with it new but not necessarily worse anxieties:
“I just remember being fearful. You have that security of when you're on treatment and being at the hospital a lot. Even though we didn't like being there—it's uncomfortable—we were being followed, checking blood work, they're doing scans more frequently. All of that and then just kind of being let go. I remember being pretty nervous about that.” (ID 20, mother, sarcoma)

“This may sound silly but there was a withdrawal. When you lean on the nurses and doctors as much as we learned to do on treatment, it was kind of scary.” (ID 18, mother, leukemia)

“When we ended treatment, it's obviously scary because you go from seeing these doctors multiple times a week, multiple blood checks, and kind of through the treatment process you're getting constant reassurance that things are working and things are fine.” (ID 16, mother, non-Hodgkin’s lymphoma)

Regardless of how parents compared anxiety at EOT to the challenges of treatment, parents unanimously perceived the end of treatment to be marked by a distressing sense of absence. The security of regular clinical relationships dissolves: “You're suddenly off treatment and all the support you've had from doctors, nurses is gone” (ID 16, mother, non-Hodgkin’s lymphoma); “I feel like initially it was hard because you go from, ‘OK she's having chemotherapy every day,’ to nothing. And then what do we do next?” (ID 6, mother, leukemia);
“It kind of feels like they just drop you” (ID 4, mother, optic pathway glioma); “I felt pretty alone” (8: mother, leukemia).

The security of a clinical roadmap disappears as well: “We don’t know where to go. . . . We’re kind of left to figure things out on our own” (ID 3, father, medulloblastoma); “You sort of feel like you’re a ship in open waters” (ID 13, mother, leukemia); “I expected it to be like treatment, like here is your roadmap, and I didn't get that from the hospital” (ID 19, mother, leukemia). Finally, some parents experienced an absence of social support around EOT: “Your friends just aren't the same after you get out and you don't look at the world the same” (ID 7, mother, neuroblastoma); “Friends and family just can’t wrap their brains around [EOT being difficult]” (ID 15, mother, sarcoma); “There are things that [child’s] friends, my friends, just don’t get and understand about [EOT being difficult]” (ID 9, mother, leukemia).

These various ways parents sensed absence at EOT led them to reflect on the lack of preparation for the distress of transitioning off treatment.

“Transition still to this day is very difficult. When we were discharged from the hospital we were prepared for what to expect medically, what we should be watching for in terms of fevers and what to watch for until his counts came back and we were prepared for what we needed to do and who to call for anything like that. The emotional and mental toll that it took on all of us though… there were no resources given to us as to where we needed to go or who we should see.” (ID 12, mother, non-Hodgkin’s lymphoma)
“Besides getting the new roadmap for off-treatment, I don't feel like there was a whole lot of preparation. It was just, ‘You're not going to need to come see us as much.’” (ID 18, mother, leukemia)

In contrast, one parent reported having a farsighted oncology team that prepared her for the emotional challenges of transition:

“Our oncologist and nurse practitioner had kind of been preparing us [for EOT and survivorship] from day one which I think is key even when you're in the beginning of it. They’d been preparing us for the transition to survivorship and that transition of care.” (ID 6, mother, leukemia)

Others felt that sufficient preparation was not possible. As one father stated, “I don’t know if there’s a way to really prepare. . . . I don’t think anyone could’ve really prepared us for [EOT] (ID 3, father, medulloblastoma). Yet, parents commonly reflected on the need for repairing emotional damage from treatment and EOT: “After treatment ended, I probably should've got therapy because psychologically you're so different” (ID 7, mother, neuroblastoma); “I think just getting therapy, that's the hardest one because at the end of treatment the post-traumatic depression happens. It happens, and I think everybody needs to actually acknowledge it” (ID 11, mother, leukemia).
IV.3 Transition into long-term survivorship

For many parents, the acute sense of distress experienced around EOT gives way to a lower-level chronic concern about the long-term late effects of treatment and preventive health behaviors that might mitigate them. After the initial distress of losing the safety and security of clinical treatment and associated relationships, parents report finding “a new normal” (ID 3, father, medulloblastoma; ID 18, mother, leukemia; ID 19, mother, leukemia). The immediate post-treatment late effects with which parents reported coping were largely physical and included fine motor deficits, gross motor deficits, hearing loss, neuropathy, stunted linear growth, fatigue, excessive weight gain, and endocrine dysfunction. Even when there was no apparent post-treatment physical dysfunction, some parents and children had to learn to cope with new physical realities of treatment such as the two parents of survivors (optic pathway glioma and retinoblastoma) who reported difficulty coping with the loss of the child’s eye, managing a new prosthetic eye, and the emotional and social changes that followed. This immediate post-treatment transition period was seen by parents to last between 6 months and 2 years, and was not concluded by sudden changes in the child’s health status or parent’s distress levels. Instead, parents report a slow shift from coping with immediate late effects and the fear of cancer recurrence to anticipating the challenges of long-term survivorship.

“We're almost to the two-year mark. So now we have to worry about other things. So now I'm starting to be more concerned about the long-term. We're not just worrying about, “OK let's get through the next 18 months to 2 years.” But now we're ready to worry about the next five years or the next ten years. What can we do for him until he turns 17? What
can we do when he turns 27? That's where we're starting to go with now. I don't feel like
worrying about the short term anymore. I'm now starting to worry about the long term
and what it's going to be like when he's an adult and teenager when I'm not there all
time.” (ID 12, mother, non-Hodgkin’s lymphoma).

“I think I have an awareness that things are probably going to pop up at some point. So,
the fact that we did so well for eight years and then it was like, wow, OK, now [health
problems] are starting to pop up.” (ID 8, mother, leukemia)

This transition into a concern for long-term survivorship health was not unanimous, however.
One parent’s child was three years removed from treatment and continued to have significant
limitations in motor function. He reported a desire to focus on the present:

"I would say we probably live more on the side of the fence of, ‘Let’s really focus on
today.’ Like, what can we do today that's going to be the best thing for her now… It’s
more short term. We're going to cross bridges when we get there.” (ID 3, father,
medulloblastoma)

The long-term late effects in survivors that many parents report are psycho-social as well
as physical. Poor emotional regulation, anxiety, cognitive delay, and poor social functioning were
commonly reported as current health problems that parents see as being potentially long-term.
The focus on long-term late effects led parents to turn their attention to preventive health behaviors.

“A big push for us now [4 years since EOT] with him is to be active. . . . We really push him to be active because that's going to do him well. . . . I want to make sure that he consumes a lot of vegetables and fruit because I want him to have that kind of general health behavior that we should all have, but he's going to need it even more.” (ID 9, mother, leukemia)

“The first couple of years [after EOT] were hard for exercise because she didn't have any endurance and her legs would hurt a lot. So I would say two years or three years after treatment was when she was finally ready and able to do stuff.” (ID 15, mother, leukemia)

However, parents did not see this interest in preventive health behavior to be matched in clinical survivorship care. In many cases, parents reported receiving no treatment summary or survivorship care plan. These parents did not “feel like there was a whole lot of preparation” (ID 18, mother, leukemia), “not a lot of ongoing information afterwards” (ID 20, mother, rhabdomyosarcoma), and not “very pleased with the information we were given during or after treatment” (ID 4, mother, optic pathway glioma). Even when such documentation was provided, parents perceived a significant lacuna in their child’s survivorship care in regard to preventive health information. One mother reported,
“[Our survivorship care plan] throws all these things out there and it's a little too much. I don't know. I would like some counseling. I would like them to talk about things like exercise and health. Just a healthy way of life. Things you can do to mitigate the late effects that the kids are going to see and specifically with leukemias and brain tumors, we need more talk about the cognitive late effects.” (ID 19, mother, leukemia)

Other parents expressed a belief that some survivorship programs and resources must exist at the hospital but they are just not aware of them. “I'm just not aware of what I don't know,” said one mother. “Maybe I didn't ask the right questions” (ID 5, mother, sarcoma). “I imagine they do have [preventive health] resources that I just don’t know about” (ID 15, mother, sarcoma), another mother said.

While some parents desired more intensive resources such as cooking classes, child-focused exercise classes, formal health behavior education classes, and referrals to dietitians, health coaches, and counselors, other parents desired “just a conversation” (ID 4, mother, optic pathway glioma) or “a sit down” (ID 1, father, leukemia) with their oncologist to discuss preventive health behaviors in survivorship. As one parent summarized, “I think just having the doctors acknowledge that … after diagnosis you can do things that are going to help.” (ID 7, mother, neuroblastoma). Some parents with older children, expressed desire for the oncologist to discuss directly with the child the importance of preventive health behaviors “because it would reinforce what I'm saying.” (ID 8, mother, leukemia).
IV.4 Gender roles

Both mothers and fathers reflected on the ways gender relationships determined how treatment and survivorship were experienced. For fathers, there was “a division of labor” (ID 2, father, rhabdomyosarcoma) in which parents “picked our roles” (ID 1, father, leukemia). This division was characterized by the mother taking the lead role as caregiver for the child, disease expert, and primary liaison with doctors and therapists: “The information flows through [my wife]. She’ll tell me, ‘Hey, this is something that’s really important. . . . I just trust her” (ID 1, father, leukemia); “[My wife] has had most of those conversations with doctors and I help her execute that on a daily basis. But I take the back seat in terms of that and just help and support whatever she wants to do” (ID 2, father, rhabdomyosarcoma). This common pattern was seen to lead to a lack of social support for fathers: “I don't think through this process that dad's are championed a ton, right? You know, there are ‘Momcologists’ and all those things and just to be honest, like, yeah, I didn't see a ton of dads [in parent support groups]” (ID 3, father, medullablastoma). One mother echoed this sentiment: “There's not a lot of support for dads. Even though they love their children just as much as the moms do, they deal with it differently than moms. It's a totally different experience. And there's a lack of support for them” (ID 14, optic pathway glioma).

While fathers saw the division of labor as primarily concerning medical information and adherence rather than direct caregiving, some mothers saw the division of labor as fundamentally structuring the childhood cancer caregiving experience. As one mother reported,
“I think he had an extremely different experience than I did. You know because I went to [treatment] alone with [child]. . . . He has a job and everything, so I just don't think we had the same experience. (ID 15, mother, sarcoma)

I'm his mom. Not that dads don't know best but you know I was the parent that was there the majority of the time. I was the one that lived in the hospital. I wasn't going back to work. And I was the one who experienced it all. Not that my husband didn't do anything, but you know he had to go back.” (ID 12, mother, non-Hodgkin’s lymphoma)

These different experiences often led to the mother making final decisions on medical care, and the father following her lead. These patterns implicitly extended into survivorship care as evinced in the unanimous responses in the negative by mothers to the question: “Does your spouse feel differently than you about your child’s survivorship care and available survivorship resources?”

IV.5 Theoretical model of experiential trajectory of survivorship transition

An emergent grounded theoretical model, presented in Figure 4.1, was developed to represent common patterns of parent caregiving experiences in the context of childhood cancer survivorship. The integrative themes that emerged from individual codes and intermediate themes revolved around narrative trajectories in which each new experience that related to childhood cancer was made sense of as a reflection on the immediate prior experience and an anticipation of the phase that was perceived to follow. Each new stage in the childhood cancer
journey was interpreted through direct reflection on the previous stage and in anticipation of the stage that was expected to follow.

The unexpected feelings of security and safety that parents reported when recalling their child’s cancer treatment were commonly seen in the context of reflections on the jarring disruption of the EOT transition. The disruption of the transition was felt acutely because of the juxtaposition between the security of treatment and uncertainty about what survivorship held in store. The immediate post-treatment phase of survivorship was unanimously experienced as a time of uncertainty as parents struggled to find new sources of the routine, supportive, and secure relationships they felt during treatment. The uncertainty surrounding EOT was seen to fade for

Fig. 4.1. A model of the experiential trajectory of the clinical transition off treatment and into long-term survivorship for parents of young childhood cancer survivors
most parents as a “new normal” was established. However, this new normal was often marked by additional, emerging challenges with survivors’ physical and mental health, school performance, and social functioning. The recognition of the persistence of these challenges, and a desire to reduce anxiety and uncertainty, initiated a transition from the ambiguity of the immediate post-treatment phase into a more stable long-term survivorship phase. In the latter, parents shifted their focus to late-effect management and long-term health-risk prevention. Concerns about cancer recurrence slowly faded in this period, replaced by concerns about what survivors’ lives would look like decades in the future. In this latest phase, parents expressed disappointment that clinical late-effect management felt disjointed and pieced together between several different specialists, a primary care doctor who seemed unprepared to care for a childhood cancer survivor, and a long-term follow-up oncologist who was seen rarely and focused primarily on screening.

The gendered differences in caregiving experiences throughout this experiential trajectory meant that mothers reported experiencing each phase and transition more acutely than fathers. The division of labor, reported in the previous sub-section, led fathers to take an ancillary role in treatment, which extended into survivorship care. However, fathers reported similar trajectories that began with the difficult but secure context of treatment, followed by the uncertainty of EOT, and concluded with a focus on long-term late-effect management and disease prevention.
V. QUALITATIVE RESULTS 2: SUPPORTIVE SOCIAL MEDIA USE

V.1 Social Media Engagement Processes

Parents of CCS who were interviewed unanimously reported seeking support through social media within six months of their child’s cancer diagnosis. The motivations for seeking support through social media varied between needing to connect with other parents who have similar disease experiences and needing additional information about their child’s condition and supportive care. Parents used the words “friend” and “friendship” to describe the relationships that developed with other parents of CC patients and survivors. The relationships grew, however, out of disease-related homophilic sorting, as parents initially searched for social media “groups that make us feel normal” (ID 6, mother, leukemia). Homophilic sorting, as described in the introduction, is the process by which homophily—a sociological phenomenon whereby similar individuals are more likely to have strong social ties than dissimilar individuals [70]—leads to selective sorting in which similar individuals freely coalesce together without higher-level organizational control.

Parents appeared to engage in such sorting first on disease type and second on phase in the cancer journey (newly diagnosed versus long-term survivorship). Parents expressed a strong desire to find and communicate with other parents of children diagnosed with precisely the same cancer type and sub-type. Parents of children with extremely rare cancer types, such as ovarian germ cell tumors, expressed especially strong desires to find experientially similar peers. As one mother reported:
“There's not a lot of us out there. It's not common. I'd never met anyone who knew it. [A mom] contacted me on Facebook because she had seen my daughter's story [on a cancer-related website] and asked me if I would join the group and so I did. And from there I have found a lot of support from people that understand where we're coming from.” (ID 5, mother, ovarian germ cell tumor)

Seeking experientially similar peers on social media quickly led to finding and joining private Facebook groups of parents with children of the same diagnosis. One mother described how she met other parents and eventually found Facebook groups:

“Especially with Facebook, if you connect with one parent, and they have five friends who are either parents of kids with cancer then you want to become friends with them and then they tell you about a Facebook group or they invite you to join a Facebook group. So it kind of happens organically. And then certain groups stand out to you based on your Facebook feed or maybe questions that you have that you need to ask.” (ID 4, mother, glioma)

These groups had names such as “You are not alone” or, more prosaically, “Pediatric Low Grade Glioma.” They served to easily connect parents to dozens, sometimes, hundreds, and in the case of the participating childhood cancer organizations in this study, thousands of other similar parents. Typically, however, the smaller the Facebook group, the more similar the parents. For
example, a pediatric brain tumor group may have thousands of parents, while an ependymoma (a particular type of brain tumor) group may have hundreds.

Searching for disease- and care-related information was also a primary motivator for parents to seek support through social media. While many parents were satisfied with the amount of disease-related information their clinical team provided them, they were unsatisfied with the amount or quality of information provided that related to supportive care and alternative treatments, or felt that the clinical information was not fully intelligible. Many parents expressed being motivated to seek information on social media by a concern that, as one mother put it, “I didn’t know what I didn’t know” (ID 9, mother, leukemia). She continued, “I can remember first going on and logging on and just sort of sitting back and reading a lot of different posts and certain things.” Parents reported feeling uneasy about searching for information outside of the clinic: “It wasn't like the hospital said ‘Hey, here are some groups to join.’ There wasn't anything formal like that. It was just a lot of trial and error” (ID 16, mother, lymphoma).

Parents reported starting their online searches in three ways: 1) a broad search using the Google search engine with their child’s specific diagnosis alongside the terms “parents” and “mothers”; 2) a Facebook search using the same terms as in the Google search; and 3) recommendations from other childhood cancer parents whom they met face-to-face in the cancer clinic. An important aspect of narrowing in on supportive social media, mentioned above, was homophily. The search terms or the face-to-face recommendations were only the beginning of a process whereby parents sought out experientially similar others with whom they could share unique and specialized support. As one parent reported, “The thing that happens is, you tend to gravitate towards other parents who are in the same position that you are. So the parents who I
became actual personal friends with... you're on a [childhood cancer Facebook] group and then you can become actual [Facebook] friends with [them]” [ID 4, mother, CNS tumor]

V.2 Social Support Through Social Media

Once parents found one or more childhood-cancer-related Facebook groups that fulfilled their perceived needs, their accounts of using these groups and interacting and developing relationships with other parents in these groups demonstrated that parents received and gave several distinct types of social support. In theoretical and psychometric work on social support, the construct of social support is commonly defined as real and perceived resources shared

| Table 5.1. Dimensions of social media social support among parents of childhood cancer survivors |
|-----------------------------------------------|--------------------------------------------------------------------------------|
| **Support Type**                          | **Definition**                                                                 |
| Emotional support                        | Communication of love, esteem, value, and affective investment in another’s goals and wellbeing. [80, 81, 85] |
| Informational support                    | Communication of facts, strategies, conceptual models, and conjecture between individuals with the intention of helping someone solve a problem or achieve a goal. [85] |
| Experiential support                     | Communication of belongingness based on similar, usually challenging, often traumatic, experiences. Informational, emotional, and appraisal support may emerge from experiential support. However, the unique benefit of experiential support is a sense of belonging and normalcy in the context of coping with an unusual and influential life experience. [78, 81, 82] |
| Appraisal support                        | “The communication of information that is pertinent to self-evaluation and encompasses expressions that affirm the appropriateness of emotions, cognitions, and behaviours.” [82] |
through social relationships [81, 101, 102]. Such resources range from the emotional (e.g., affection and value) to the informational (e.g., explanations and advice) and the practical (e.g., assistance or tangible goods). In Table 5.1, the four types of social support that emerged from iterative thematic coding are defined. Although emotional and informational support are the most commonly measured and studied types of social support, finer distinctions have been made by researchers focusing on peer social support in health contexts. The two most relevant types of peer support in these contexts are experiential support and appraisal support. Experiential support is the communication of belongingness in the context of experiencing an unusual life event that disrupts normal belongingness in previous social networks [78, 81, 82]. Appraisal support has been recognized as a type of social resource that involves communication relevant for self-evaluation and the regulation of appropriate emotions, thoughts, and behaviors [81, 82].

V.2a Emotional Support

When parents joined childhood-cancer-related Facebook groups, they reported that over time, durable and meaningful relationships developed with other childhood cancer parents in these groups. These relationships commonly extended beyond social media and into telephone and in-person contact. As one mother noted, the other mothers she met in Facebook groups have become her most intimate friends. “I think at any point in time these friendships, I could call these moms at three o'clock in the morning if I had a concern and they would answer the phone and be there for me, you know, because they're going through the same thing. It's a 24 hour thing. You're dealing with it every day. So that's emotional support” [ID 13, mother leukemia].
Not all emotional support was from parents who became close friends. More often, posting to a Facebook group would elicit emotional support from dozens of other parents, many of whom were strangers and would remain so. Nevertheless, such support was meaningful. As one mother reported,

“When I post a question on there and the outpour of comments that I get are incredible. You know, if I’m having a bad moment and I’m like, ‘Is this normal?’ And you go check your facebook and you've got 120 notifications saying, ‘Girl, you've got this.’ ‘Mom you're OK.’ ‘This is normal, don't worry about it.’ That, as a mom, made me feel good knowing I wasn't alone when in the midst of it all you felt you were nothing but alone” [ID 12, mother, NHL].

Further, not all emotional support received on social media was from other childhood cancer parents. Several parents reported receiving emotional support from Caringbridge, a social media platform designed for parents to create a page and share health updates on a child with a medical condition. “I had a Caringbridge page,” one mother reported, “and I really did appreciate the feedback I got on that. That was really important to my husband and I when we would get feedback from a message or post” [ID , mother, leukemia].

Emotional support was often seen not as a distinct type of support but rather as blended with other types of support. As one parent noted, "Parents just need the emotional, spiritual, and educational support to all be blended together to help them through this and not to suffer from PTSD. I live in a small town, so I get this support from my [Facebook] group” [ID 13, mother,
leukemia]. And another: “The retinoblastoma moms group, they really are incredible and you can turn to them for so many different things. We talk about chemicals in our homes or just rough days for ourselves, having a little bit of PTSD. I mean anything and everything is welcomed on there. We're just true support for each other” [ID 10, mother, retinoblastoma].

V.2b Informational Support

Parents reported receiving informational support in both targeted and general ways. Targeted information was commonly elicited for questions parents had about deciding between treatment options, ameliorating treatment side-effects, or interpreting lab reports. One parent recounted building up the confidence to ask a question to a large childhood cancer-related Facebook group:

“I'll never forget asking my first question. It was specifically about a lab report and not really understanding what it meant. I think it was how do you figure out an ANC. It was like within a minute that there was a response and then it became more and more comfortable to ask questions because I knew that I wasn't going to be judged. And you could have a place where you could express your fears without anybody else knowing. And you know that you're not going to be judged in regards to that because you know as a parent of a child with cancer you just you go on and do the best you can.” [ID 9, other, leukemia]

More experienced parents in disease-specific Facebook groups were seen as highly reliable sources of information. As one mother noted, “I would go mostly to [experienced] moms first and then whatever their suggestions would be, I would go with that to the doctor. Because
sometimes these moms have other ideas or other spins on things that I never thought of” [ID 13, mother, leukemia]. Often, however, parents used the groups’ feeds (i.e., the scrolling update of posts in a group) to gather general information and learn in an undirected way. “I remember first going on,” one mother recalled, “and just sort of sitting back and reading a lot of different posts and certain things. It took me a long time to make any posts and to ask a question” [ID 9, mother, leukemia].

Parents were motivated to stay in Facebook groups long after needing them for treatment-related information. Serving as an experienced parent who provides information to newer parents became a motivating factor. “I feel that when I see something posted by a mom who’s concerned,” one mother reported, “I’m able to help them out before they waste a lot of time and money” [ID 11, mother, leukemia]. Another mother explained:

“Sometimes I don't want to get drawn into [the Facebook groups] but at the same time I feel like I wish I had that [earlier]. I wish I had been able to put it on Facebook and say, “Has this ever happened to anybody?” And have at least one person come back and say it happened to me. Because you're in the weeds…. In these groups you become emotionally attached to these other parents. . . . Now I’m on [Facebook] groups for BMT and the AML ones not because I feel like I need anything but because there's been a couple instances where like for us, where someone has not grafted with the cord and I remember feeling like completely alone and we were totally frightened and we didn't know anybody who ever had had this case. . . . But I didn't want people to feel like they had to lose hope.
because at least with us, our son is still with us. And he actually did really well once he got the transplant” [ID 8, mother, leukemia].

Parents did not report a desire to offer broad, general advice to newer parents. Rather their desire was to use their specific experiences to provide targeted informational support when another parent requested it. As one mother explained, “If someone's asking a question and I think I can add value, I will respond to them. But I don’t just go on and offer random advice” [ID 5, mother, germ cell tumor].

V.2c Experiential Support

Due to the unique features of each cancer type and treatment regimen, parents found the greatest support with others who shared the same diagnosis and treatment plan. While some of the communication between experientially similar parents was informational in nature—focusing on treatment options, lab reports, diagnostic scans, and side-effects—many of the perceived benefits revolved around feelings of belongingness. The child’s cancer diagnosis, treatment, and continued health challenges after treatment served as a marker of difference that disrupted the social networks of family and friends in which parents previously belonged. The “comfort” [ID 5, mother sarcoma; ID 9, mother, leukemia; ID 10, mother, retinoblastoma; ID 3, father, CNS tumor] and “safe place” [ID 6, mother leukemia; ID 10, mother retinoblastoma] provided by Facebook groups of experiential similar parents produces a sense of belongingness that was meaningful to parents apart from its instrumental value of gaining disease-specific information.
Parents sometimes reflected on this belongingness as providing a space of support where its most beneficial feature was absence—of judgment and of needing to explain oneself:

“I don't feel like I'm going to be judged or anything for asking them crazy questions. I think that they're just as supportive, almost more supportive, than some of the cancer moms that I know in real life because those cancer moms [in the Facebook group] have gone through the type of cancer that my daughter has versus the ones that I know in the real world that have gone through other types of cancer, that sympathize but can't really understand. . . . Just like I can't fully understand their journey as much as I want to, they can't fully understand ours. So I feel like the ones online understand us more so than others just because they've gone through a lot closer of an experience.” [ID 5, mother, germ cell tumor]

An ease of communication that is present among experientially similar peers was a defining feature of these Facebook groups. There was “comfort” parents expressed in knowing that other parents in these disease-specific groups were experiencing or have experienced the same difficult and unusual circumstances:

“In all honesty, I don't know what I would do without [other parents in the disease-specific Facebook group]. It's still so nice and comforting to be able to communicate with people that can relate to it and feel the same way. . . . We’re like a family, all of us. I think
it's a safe place to come, talk, brag. Whatever it is that you want to talk about with your kids.” [ID 10, mother retinoblastoma]

One of the most meaningful benefits of these Facebook groups was the willingness to engage and communicate about cancer and its sequelae long after diagnosis and initial treatment. While friends and family may be eager for the cancer-affected family to return to normal life, parents have continuing concerns and challenges as their children transition into long-term survivorship. As one parent explained, “When I put something on [my personal Facebook page] regarding her eye or regarding childhood cancer it doesn't get much attention. The moms in the retinoblastoma group acknowledge it. They are in our shoes so it's important to them” [ID 10, mother neuroblastoma]. Experientially similar parents do not urge each other to return to their pre-cancer lives, but rather work to find a “new normal” [ID 13, mother, leukemia; ID 17, mother, leukemia; ID 6, mother, leukemia; ID 11, mother leukemia] that includes childhood cancer rather than erasing it.

V.2d Appraisal Support

The fourth type of support parents reported was a form of communication between experientially similar parents that signaled what types of emotions, thoughts, and actions were appropriate in these new, uncharted circumstances. First, as they navigated the new world of diagnosis and treatment, and later as they navigated the world of survivorship, parents sought experientially similar peers on social media to find signals that would help guide action in these new environments. Throughout the cancer journey, from diagnosis to long-term survivorship,
questions around what emotions, thoughts, and actions are appropriate emerge anew at each stage. Post-treatment was a particularly anxiety-producing period because the network of support provided by supportive staff, nurses, and doctors appeared to suddenly vanish. The appropriate response to a fever during treatment is not necessarily appropriate after treatment ends. One mother recounted her experience a few months after the end of treatment:

“The first time off-treatment I saw he had a fever of 102, and I thought, ‘I need to call the hospital.’ But I instead got on [to the Facebook group] and said ‘OK what do I do?’ Because I couldn't think past: I need to call and have them get him a room ready so they can have the antibiotic ready for when we get there to pump through my child. Like if he had a port and was on treatment. And so it was this, ‘A-ha, OK here we go. Here's how we do it normal-kid-style.’ So it was these other moms reminding me, like I said, normal-kid-style. So yeah that was the first after care or off treatment group moment. And they all said, ‘Hey, we all had this moment, it's OK.’ And so they pass the baton.” [ID 18, mother, leukemia]

Self-evaluation remains a salient issue long into survivorship for many parents as they continue to navigate new challenges with their survivor children. As one parent described:

“I get the understanding [from the Facebook group parents] that it's OK to feel hurt. We kind of understand each other because [friends and family] just keeps telling you, “You can move on with life. Everything's OK. Your daughter survived. You should be able to
go back to normal.” With [the Facebook group] I can go ahead and be open about what I feel and the support that I get from them is the understanding and the pain that they're also dealing with and how we can connect and the fact that yes, it's OK for us to feel what we're feeling and that it just takes a while for it to change. It's not going to happen overnight like everyone wants it to happen. It's different. The connection there, I don't think I could have that understanding from my mom or my sister the way I have it from the [Facebook] group.” [ID 11, mother, leukemia]

Appraisal support was also nuanced; emotions, thoughts, and actions that were inappropriate among friends and family could be not only appropriate but welcome within the Facebook group of experientially similar parents. When one parent first found her disease-specific group, she was taken aback by some of the angrier expressions by parents in the group:

“There were a couple parents [in the Facebook group] who were just super angry and that didn't scare me or upset me in any way. That made me feel like, OK I'm not alone. You know I was angry too. But you can't really go around the hospital being super angry. You can't actually be angry at all. So there was my little piece to see that other people were angry and upset and sad and all those things but anger was the big one. You know, why is this happening? You know it's nice to see other people express that. It makes your emotions feel like they're not so alone. It makes you realize that oh yeah, other people have that.” [ID 13, mother, leukemia]
V.3 Positive and Negative Experiences on Social Media

When recounting positive experiences in disease-specific Facebook groups, parents most commonly referred to homophily, that is, moments in which they connected with other parents who had identical experiences, such as child’s diagnosis and treatment regimen, and similar parent characteristics, such as children’s ages and genders. The connection over long distances that Facebook affords is only one component that allows for this homophily. The other component is the widespread use of Facebook. As Fig. 3.3 showed, parents of CCS were far more likely to use Facebook daily than other social media platforms. As more parents use Facebook, the likelihood increases that not only will parents with rare diseases find each other, but within these disease groups, parents who are more alike (along a number of dimensions) will find each other, communicate, and develop close social ties. As the previous section on social support demonstrated, these ties do much more than only serve as a medium for sharing informational resources; they become a medium for the same social resources that flow through the close social ties of friends and family. As one mother described:

“There are probably three moms whose kids have optic glioma tumor that I connect with the most. And we all have children who are about the same age. We live in four different parts of the country and they really did support us. Like when we went on our Make-a-Wish trip a couple of years ago, one of them sent [my child] a camera just in the mail and said, “When we went on our trip, [my child] loved her camera so we wanted to send one to [you].” And then another family who had a young child who has the same diagnosis as
[our child] and it's the same treatment, they actually helped us raise money in the very beginning before their child had to start treatment.” [ID 4, mother, CNS tumor]

Although other resources were shared in these relationships, many of the positive experiences on social media recounted by parents were related to information sharing. There was a recognition, especially among parents of children with unusually rare cancers, that their oncology team may not have access to all of the available and relevant information on their child’s condition. Parents are also eager to share their specialized, hard-won knowledge after treatment ends. One mother described sharing her experience with a young adult cancer patient:

“My daughter has [a] syndrome which is really rare. I've never really met anyone that had it, let alone someone that's had a child [with it]. And one of the support groups that I'm part of is, there's the pediatric one but there's also one for germ cell cancers that are not just for the pediatric but for adults as well. And there was a 27-year-old lady that had just been diagnosed with [this] syndrome and it had wrapped around her liver just like my daughter. And she was going on the Facebook support group saying, "Hey I was diagnosed with this. I don't know what to do. I don't know what the next steps are? My oncology team hasn't come back to tell me anything yet." And I ended up talking to her a little bit, saying, “Hey, I understand where you're coming from a little bit on this. My daughter had it and we were talking and I was able to give her the experimental chemo that my daughter had taken every month and she hadn't heard of that before and I said I can't guarantee that this will work but it has on some patients. And I was able to tell her
what they did for my daughter to help remove it.” [ID 5, mother, Ovarian germ cell tumor]

Some positive experiences recounted were not related to parents connecting but rather their affected children connecting. The potential decrements in social functioning of children in and after treatment is well documented [103–106]. Parents of children who have been visibly affected by cancer treatment, such as losing a limb or an eye, were particularly aware of connecting their children with similar CCS. One mother recounted the positive experience of an adolescent survivor recording a video for her pre-adolescent son:

“So there was a time when we were trying to get [child]’s prosthetic eye in and everything that we had tried, everything that we had thought of, nothing was working. And I reached out to this mom who lives in Iowa and her son was a few years ahead of [my child]. And I was venting to her and [asked], “What do I do? We're frustrated and lost.” And she was just like, “You know if you want to fly out here, you can come stay with us.” And we could meet her son and maybe that one-on-one connection with [my child] would help. And we didn't do that but her son made a video for [my child’s] showing him how to take his prosthetic in and out.” [ID 14: Mother, CNS tumor]

Parents were also asked about negative childhood-cancer-related experiences on Facebook. Most parents reported that negative social media experience related to their childhood cancer experience were exceedingly rare. The most common recollections of negative
experiences were related to parents arguing about vaccines, which often caused dissension within these disease-specific Facebook groups. However, the group moderators, parents explained, would quickly dissolve the tension by asking parents to not discuss this topic. One parent reported experiencing Facebook groups as too emotionally charged. She perceived other parents as “venting” or inappropriately asking for medical advice:

“One [childhood cancer] group I had found actually provided more anxiety for me than anything because it was a very loosely monitored group where I would go looking for support but really it's people posting like "This fever is happening." And I'm thinking, "OK this is not the venue to be asking health care questions probably." I found it more frustrating than anything because I wasn't getting what I was looking for. It seemed like too many were constantly venting.” [ID 6, mother, leukemia]

Most parents did not see venting or asking medical questions as inappropriate. More commonly, parents mentioned differences in supportive care choices as causing dissension. One mother described her experience:

“There was one time when I typed up … something about giving my son vitamins. It had to do with that. And this mom got really snarky in her response. And I was like, are you kidding me? A: I'm trying to do the right thing by even giving him vitamins. B: Instead of psychoanalyzing what I'm doing, be constructive and offer ideas and solutions.” [ID 14: Mother, CNS tumor]
Another parent reported emotional escalation as her primary negative experience:

“I think the only thing negative was when I posted in regard to [a medical mistake]. I wasn't looking for the negative. I was just looking to find out if anybody else had gone through [something like that]. At that point I was just really more concerned with my son's health and making sure that we were doing all that we could to get the information because it was so rare. And just the negative response in regard to, you know, suing your doctors and your hospital. And that was the furthest thing from my mind. I'm like, that's not what I'm looking for, people.” [ID 9: Mother leukemia]

In large childhood cancer Facebook groups that include parents in all stages of the cancer journey, parents can have negative exchanges due to their different stages:

“I've seen this a little bit when someone comes on and says, “I'm really struggling.” The child is still here but they're struggling with certain things, and sometimes other parents will be like—and I totally get this—but their child has passed away and they're really upset. And they’re like, “You're complaining about that? I would do anything to have my child." And they're just super negative. I've seen a few things where I'm like, that isn't going in the right direction.” [ID 20, Mother, Sarcoma]
An emergent grounded theoretical model, presented in Fig. 5.1, was developed to represent the process of supportive social media use among parents of CCS. The themes and sub-themes that emerged in parent narratives of seeking, finding, and using supportive relationships through social media revolved around a common process that began at diagnosis, was motivated by a need for specialized emotional and informational support, accelerated by a dearth of such support in local, face-to-face social ties, and culminated in finding closed or private Facebook groups of parents with children who shared identical diagnoses. Once in an appropriate group or groups, parents often remained active long after treatment ended because first, each new stage in the cancer journey presented new challenges that required the peer support of these groups, and second, parents reported a deep need to give support to new parents whose children were experiencing the same diagnosis, treatments, and sequelae as their children did.

In this common narrative, diagnosis was remembered as a defining moment in one’s life that marked a before and after. Before diagnosis, the natural social networks of friends, family, and co-workers provided informational, emotional, appraisal, and experiential support that was at least sufficient to meet the needs of daily life. But a childhood cancer diagnosis disrupted this equilibrium because, although these natural social networks could and often did provide high-quality emotional support, they could not provide advice (informational support), signaling of appropriate thoughts, emotions, and actions (appraisal support), nor a sense of belongingness (experiential support) in the context of this life-changing event. Common accelerants to this support-seeking were parents’ feelings of 1) needing more information than what their oncology
Figure 5.1. Theoretical model of supportive social media use among parents of childhood cancer survivors
team was providing them (either because the information was not given or because parents did not fully understand the information that was given); 2) disruption in their natural, local social networks of friends and family.

Parents used the Google search engine, the Facebook search function, and recommendations from of childhood cancer parents met in clinic. Regardless of the method, a large majority of the parents reported finding, joining, consistently interacting in, and developing close relationships through closed or private disease-specific Facebook groups. In these groups, parents reported receiving four distinct types of social support: informational, emotional, appraisal, and experiential. However, parents reported these support types as not distinct resources, but rather as blended together. Such support was not only received by parents, but the role of giving such support to newer parents was seen as a motivating factor for remaining active in these groups long after one’s child has finished treatment.

Parents commonly made a distinction between their activity in disease-specific Facebook groups before and after end of treatment (EOT). They reported EOT as a time of anxiety and emotional stress, and the network of experientially-similar peers they developed in Facebook groups helped transition them into the “new normal” of survivorship. Some parents noted that in long-term survivorship, their activity had waned, although they continued to look for new parents in these groups whom they felt they could help. Other parents made no distinction in their activity levels and remained nearly as active in the present as they did when their child was in treatment. However, the common pattern these parents shared was a desire to give back the various supportive resources they received when their child was in treatment.
VI. DISCUSSION AND CONCLUSION

VI.1 Summary of Findings

This mixed-methods study produced three sets of findings. First, quantitative analyses showed that parents currently engaged in social media report high levels of social media use (with Facebook as the predominant platform) and moderately high levels of emotional distress. Greater social media use is directly associated with greater parent-reported levels of depression and anxiety. However, social media use is also related to greater levels of OSI. Mediation analysis revealed that OSI competitively mediates the positive relationship between social media and depression, and to a lesser extent anxiety. In other words, if social media produces OSI, the potentially deleterious relationship between social media and depression is significantly weakened.

Second, thematic qualitative analysis of parent narratives of the transition off of treatment detected common patterns for parents in regard to clinical survivorship care relationships and support in treatment, transitioning off treatment, and long-term survivorship. The interview data were integrated into an emergent, grounded theoretical model that presents caregiving experiences in the context of long-term survivorship as an experiential trajectory beginning with the difficult but secure experience of cancer treatment as parents felt supported by oncology care teams and the routine of regular treatments, lab appointments, and rehabilitation therapies. The end of treatment, therefore, was experienced as a jarring interruption in support in this challenging but secure routine. This disorientation was experienced as marking a transitional phase of deep uncertainty. No single event concluded this phase; parents instead reported a slow and steady transition into long-term late effect management and focus on long-term disease
prevention. Both phases after treatment were characterized by parents’ disappointment in clinical supportive care. In the immediate EOT phase, parents simply wanted more frequent interaction and screening, largely to recreate the safety and security of the routine appointments of the treatment phase. In the final phase, parents were less concerned about frequency and more concerned about integration of clinical late effect management and the provision of preventive health resources.

The third and final set of findings resulted from a thematic qualitative analysis of parent descriptions of using and seeking support on social media. This analysis identified four distinct types of social support parents reported receiving from disease-specific social media groups: emotional, informational, appraisal, and experiential. Interview data related to social media use were thematically organized and integrated into an emergent theoretical model that illustrates the common pathway through which parents seek, find, and join disease-specific social media groups. The pathway begins, parents reported, with the life-changing event of diagnosis which caused them to seek specific and non-specific information, as well as experientially similar others who could help them “feel normal” once again. Google searches, Facebook searches, and recommendations from other childhood cancer parents met in the clinic were common methods for finding supportive resources on social media. All parents eventually found and joined disease-specific, private or closed Facebook groups, although not all found them helpful or supportive. A majority, however, reported receiving social support in the form of communication that indicated experiential similarity and acceptance, helpful advice, and emotional warmth. Also, a large majority of parents reported developing at least one close childhood-cancer-parent-friend through social media. While some parents had decreased their use of social media as their
children get further from treatment, a majority continued to stay active by offering different types of social support to new parents who join these disease-specific groups.

VI.2 Meaning and Clinical Relevance of Findings

VI.2a Quantitative Findings: Meaning and Relevance

The quantitative findings have several important implications. First, social media is a central part of the childhood cancer journey among parents who use social media. Parents reported spending an average of 20 hours a week on social media, with Facebook the most often used platform by a large margin. Around half of parents’ time on social media was spent on childhood-cancer-related groups or pages, or communicating with other childhood cancer parents. When engaging with childhood-cancer-related information online, parents reported daily use of social media that was three times higher than for any other childhood-cancer-related website, six times higher than on a WebMD-like website, and nine times higher than on a hospital’s website. Nine out of ten parents reported developing at least one close relationship with another childhood cancer parent on social media. Despite the centrality of social media in the lives of parents of childhood cancer survivors, little attention has been paid to using it for improving survivorship outcomes for survivors or caregivers. These findings suggest that clinical, academic, and community advocates for childhood cancer survivors should begin to focus on social media, Facebook in particular, as a site for interventions that can target an array of survivorship outcomes, from screening awareness to late-effect management, to preventive health behavior change and maintenance.
Second, producing strong peer social relationships should be a primary aim of social media interventions for parents of CCS. Online peer support from social media may function in similar ways as offline, real-world perceived social support. A large body of evidence links offline perceived social support to lower levels of depression and anxiety in healthy adults [107, 108] and adolescents [109, 110], adults in a variety of disease contexts, such as cancer [111, 112] and myocardial infarction recovery [113], and in our population of interest, parents of children affected by cancer [114]. While the directionality of this association is debated, longitudinal studies have shown that social support at baseline affects changes in future levels of depression [107], but that baseline depression can also affect future levels of social support [115]. If online social support is experienced in similar ways, then early engagement in social media support groups may affect future levels of depression for parents of young survivors. Given the dearth of evidence for face-to-face support group efficacy in parents of children affected by cancer, social media support groups may represent an appealing and cost-effective alternative for preventive psychosocial care in the context of pediatric cancer. Therefore, apprehensions about social media in healthcare may deserve closer scrutiny.

Thus, the second important implication of these findings is that, despite a body of evidence highlighting social media’s negative aspects [62, 116, 117], as well as our own finding that it is positively associated with depression, high levels of social media use may not be detrimental in itself. For parents of young survivors who are currently in social media support groups, the strong association between level of social media use and OSI suggests that high levels of social media may be beneficial in the right context. However, it is unlikely that it is social media alone that leads to high levels of OSI, but rather specific types of interactions in
specific contexts. Therefore, the third implication of these findings is that the structure and quality of interactions on social media are likely a crucial determinant of whether social media is protective or harmful. All of the parents in this study were members of Facebook “groups” created by parents of childhood cancer patients and survivors for parent peer support. The high levels of social media use and OSI were likely related to belonging to and interacting in these groups. Unfortunately, we do not have a comparator group of parents of CCS who are not in such groups, but the direct effect shown in mediation analysis between social media use and depression suggests that if a parent is not perceiving social support online, then greater social media use may not have a protective effect for psychosocial health. It is likely that these social media support groups contain elements that facilitate positive peer social interaction.

VI.2b Qualitative Findings: Meaning and Relevance

Transition off of treatment. The anxiety parents experience at EOT is a critical motivator of social media use. The timing of this anxiety at EOT has been identified previously. Wakefield and colleagues [32] reviewed 15 studies on the psychosocial impact of treatment completion on parents of CCS and found that these caregivers were at increased risk for feelings of anxiety, uncertainty, helplessness, and loneliness compared to non-cancer populations. They interpreted the qualitative literature they reviewed as demonstrating that parental concern over recurrence was the key driver of emotional distress in the EOT phase. Thus, Wakefield and colleagues suggest, effective risk communication targeting fears of recurrence may be the key to alleviating parent emotional distress. However, our data suggest that recurrence is just one part of a complex set of concerns parents have during the transition. This set of concerns should be
understood in the context of a common experiential trajectory, rather than as an acute or chronic miscalculation of risk.

Parents understood their distress as emerging out of a transition from a difficult-but-secure steady state of treatment in which, despite its obvious difficulties, parents felt “safe,” “secure,” “supported,” and “connected.” The common fear of recurrence was only a part of a larger complex of concern that included their child’s physical, mental, and social functioning, as well as a more difficult-to-articulate sense of lost routine, security, and support. Even after fears of recurrence subsided, all parents in the study expressed continued, yet low-level, concern about their child in part because they perceived they were facing present and future late effects without the same level of support or understanding they received during treatment. Effective risk communication may alleviate some anxiety for parents, but such interventions would be unlikely to assuage concerns over a loss of regular routine, support, and caring, nor adequately meet parents’ desire for more integrated late-effect management and long-term preventive health resources.

Our findings are congruent with studies that show, despite the difficulties of cancer treatment, parents feel better prepared to cope with that phase than they do with life after treatment. Greenzang and colleagues [18] recently estimated that 87% of parents reported feeling well prepared for their child’s cancer treatment, whereas 62% reported feeling well prepared for life after treatment. More important, their study found that at EOT both parents and clinicians dramatically underestimated the long-term health challenges survivors would face. Our data suggests that as parents move into the third phase of management and prevention, represented in the theoretical model in Figure 4.1, that parents begin to recognize the full extent of the
survivorship health challenges their child faces. The question of whether these challenges are adequately acknowledged in long-term survivorship clinical care remains open. However, this phase represents a potentially ideal time to introduce social media interventions that target late-effect management and preventive health behavior change for parents of CCS.

How generalizable is the theoretical model that emerged from our findings? Arnold [118] found a similar psychosocial response among adult breast cancer survivors to the EOT transition. These adult survivors described their need for a continued “safety net of support” after treatment ended. As in Wakefield and colleagues’ review of studies on parents of childhood cancer [32], a central concern was recurrence. However, these adult survivors also expressed a loss of social support, routine, safety, and direction that treatment offered. Treatment was obviously comforting because patients saw it as effectively treating their disease. But the social and institutional apparatus that surrounding the provision of chemotherapy was just as important to their psychosocial wellbeing. Our findings suggest that this is a potentially common theme for the experience of the cancer journey for both caregivers and patients.

These findings have several implications for supportive care after EOT. First, social media interventions that target psychosocial preparation may help parents anticipate the jarring transition to EOT by encouraging them to draw on both local and online social networks for support and engage in effective anxiety-reducing practices like mindful meditation and physical activity. Appraisal support among experientially similar parents may aid in understanding that EOT is not only a time of joy but can also be stressful. A well-designed social media support intervention may provide parents with a sense of orientation in an otherwise disorienting period. Second, more accessible care during the transition off-treatment may provide parents with
extended feelings of safety and security they felt during treatment. One solution that would avoid burdening clinical care teams would be the development of social media interventions that could connect parents to more experienced parent-peers at EOT. Peer health coach models have been developed and evaluated with success in other contexts [119–123], and may be ideal for parents at EOT who not only seek reassurance about the future, but also have many immediate caregiving concerns. Finally, a significant gap in preventive health behavior education and support could be addressed, again with minimal burden on survivorship clinic resources, through social-media-based preventive health programs. Additionally, there is a need for both clinicians and parents to advocate for increased research and programmatic support in preventive health for CCS.

**Online Social Support.** Several previous studies have demonstrated the high levels of online activity and the perception of various types of social support on social media among parents of children with childhood cancer [29, 50] and other serious medical conditions [30, 54, 57]. However, because this research is focused on assessing cross-sectional behavior and perceptions among parents, no qualitative research exists on how parents of childhood cancer patients or survivors seek, find, and engage with parent-peers on social media. In the qualitative phase of this study, parents were asked to narrativize their cancer-related social media behavior, from their initial online search to the present. These narratives allowed for thematic coding analysis that produced a model for social media support seeking among parents of childhood cancer survivors. This model illuminates the processes through which parents commonly seek and engage with socially supportive resources on social media.
There are several relevant implications for researchers and clinicians interested in developing or using social media interventions that target parents of childhood cancer patients and survivors. First, when considering the timing of introducing a social media intervention, the six-month period after diagnosis appears to be an important inflection point. This period is experienced as radically unsettling in a variety of ways. The informational deficit parents experience is only one motivating factor; the disruption in their normal social networks of family and friends is also motivating. Introducing a peer-support-based intervention at this time would likely receive a high level of interest from parents. Although, no parents reported finding new Facebook groups around EOT, the high level of emotional distress experienced around this time period in conjunction with parents’ new questions and concerns may serve as another entry point acceptable to parents. Second, researchers designing social media interventions targeting improvement of knowledge and skills should consider how important non-informational social support is for parents using social media and Facebook groups in particular. Emotional, appraisal, and experiential support were seen by parents as “blended” together. Interventions that focus on social media as a simple communication platform for pushing out information, or even a platform for expert communication with dialogue, will miss supportive and salient aspects of social media technology. The data collected in this study cannot illuminate how to leverage social media platforms, but it can direct researchers’ attention toward promising avenues of inquiry. Social media mechanisms, such as posting photos, use of emojis, video chat, and group creation and design should be tested to examine their utility in increasing perceptions of emotional, appraisal, and experiential support. Increasing informational support may be the lowest hanging fruit, but these other types of support may prove to be the most important if they
produce high levels of adherence and satisfaction with the intervention. Furthermore, theoretical mechanisms such as social modeling [124–127] would be activated through high levels of peer support and thus may be leveraged to produce change in targeted behaviors. Third, appraisal and experiential support in social media groups depend on experiential similarity among the group members. Parents reported a strong desire for finding and engaging with other parents whose lives had been changed by the exact same cancer diagnosis. A group of parents whose children were diagnosed with a leukemia or a brain tumor was only minimally sufficient. In these groups, parents often posted looking for other parents with children with precisely the same diagnosis. Developing social media interventions that connect parents with very similar diagnoses may provide an advantage of quickly bonding participants and engendering high levels of engagement and activity. Fourth, some of the most salient memories for parents engaging in childhood-cancer-related social media were related to connecting with other parents who were further along in the “cancer journey,” or providing that experienced parent perspective to a new parent. These interactions were the locus of appraisal and experiential support that parents found particularly valuable. Social media interventions that train and use peer coaches may be able to regularly provide this support at scale.

VI.3 Limitations

**Quantitative Phase.** Limitations of the quantitative phase of this mixed-methods study include, first, its sample selection and cross-sectional design. Sample eligibility was limited to parents of survivors who were at least 1 year off treatment yet under 13 years old. These narrow inclusion criteria served the purpose of examining parents who are likely to have maximal
control over the health behaviors of their children, a variable of focus in the larger mixed-methods study from which these data were gathered. However, this criterion restricted us from examining parents of survivors in the adolescent and young adult (AYA) population, where parents remain an important focus. Also, because recruitment was conducted only online (via email and Facebook recruitment messages), we cannot compare psychosocial outcomes of parents who are not users of social media. Additionally, the sample size is relatively small in comparison with the large size of the Facebook membership of the groups targeted for survey recruitment. Unfortunately, we do not know the number of parents who were reached by the recruitment messages as Facebook does not provide such data. Messages posted in Facebook groups are typically seen when they populate in an individual’s personal news feed. The chance of a group post showing up in a personal feed is determined by a continuously updated Facebook algorithm. We also do not know how many parents in these groups were ultimately eligible because, although each non-profit organization keeps membership data for parents who sign up over the web, parents may join each group without signing up through the organizations’ web page. Thus, there is no comprehensive database for either Facebook group that contains information on total number eligible. Nevertheless, each parent who completed the survey gave their email address, child’s diagnosis, and zip code which allowed us to confirm no duplicate responses were given, a problem identified in online survey research [128]. The homogeneity of the sample also limits our ability to generalize beyond well-educated, white mothers. While this is not unusual in samples of parents of CCS [18], future studies should seek additional recruitment methods to reach a more diverse sample. The convenience sampling method of this study used two large childhood cancer organizations’ online support groups for participant
recruitment. The parents who join such groups represent a self-selected sample of all parents of childhood cancer survivors. This bias is likely increased in the sample that responded to the recruitment messages. The effect of the cross-sectional design of the study on inferring causality has already been addressed. Further challenges with the design include the impossibility of examining how changes in social media use affect changes in social support and depression over time, particularly from in-treatment to off-treatment status.

**Qualitative Phase.** The qualitative phase of this study also has several limitations. Like the quantitative phase, it is a small, cross-sectional study and thus did not follow participants over time. The heterogeneity of our sample of caregivers also limits our ability to draw specific conclusions relating to individual subgroups of caregivers such as those with specific diagnoses, treatment exposures, or sociodemographics. Nevertheless, the diversity of family location and experience in diagnoses indicates that emergent patterns represented in the theoretical model may not be strongly influenced by geography and cancer type. Additionally, the overrepresentation of mothers in this sample may have biased the results. The three fathers in our sample reported similar experiences across their cancer journeys in regard to transitioning off-treatment, although from the perspective of an “assistant” to the lead caregiver. It is likely that had we recruited more fathers for interviews that we would have recorded accounts of different experiences of fathering a childhood cancer survivor. Finally, our qualitative sample was selected from a larger sample that was recruited through private social media support groups for parents of CCS. Thus, we did not recruit parents who did not use social media. Because the focus of qualitative data collection was on experiences of EOT, long-term survivorship, and supportive social media use it is unknown how non-social-media-using parents’ experiences may differ.
VI.4 Conclusion

The findings of this mixed-methods study suggest that social media interventions for parents of CCS are warranted. While social media use among parents of CCS is positively associated with emotional distress, when parents experience strong and positive social relationships on social media, the association between social media use and distress is dramatically attenuated. It may be that interventions designed to increase positive social relationships on social media will significantly improve parent distress. Qualitative results showed that social media interventions may be particularly acceptable to parents shortly after diagnosis and around end of treatment. Qualitative data also showed that parents reported several distinct types of social support, with experiential and appraisal support as unique resources that emerge from experientially similar peers finding each other and interacting over social media. Together, these mixed-methods data suggest that social media interventions that connect experientially similar peers shortly after diagnosis or around end of treatment in ways that produce close peer relationships may garner high levels adherence and satisfaction while attenuating parent distress.
APPENDIX A: Quantitative Survey Measures

Participant Information

Below are a few questions about you and your childhood cancer survivor. Thank you for your participation!

Thank you for participating in this survey! Your answers will help other parents!

1) If you would like to be entered into the gift card drawing or are willing to participate in a later telephone interview about parenting a childhood cancer survivor, please enter your email address.

2) I am willing to participate at a later date in an hour long interview about childhood cancer survivorship over the phone or computer.

3) Which online group do you use most often?
   ○ MaxLove Project SuperFamilies Support Group
   ○ Momcology Support Group

4) What was your child’s age (in years) at diagnosis?

5) What is your child’s current age?

6) What was your child’s diagnosis?
   ○ Bone tumor
   ○ Brain tumor
   ○ Hodgkin’s disease
   ○ Leukemia
   ○ Non-Hodgkin’s lymphoma
   ○ Neuroblastoma
   ○ Sarcoma
   ○ Wilm’s tumor

7) What type of treatments did your child receive?
   ○ Surgery (brain)
   ○ Surgery (non-brain)
   ○ Radiation
   ○ Chemotherapy

8) What is your current age?

9) Your home ZIP code (if not in the US, please list country)

10) What is your gender?
    ○ Female
    ○ Male

11) What is your child’s gender?
    ○ Female
    ○ Male

12) Your Race/Ethnicity
    ○ Hispanic or Latino
    ○ Non-Hispanic black
    ○ Non-hispanic white
    ○ Asian/Pacific Islander
    ○ American Indian/Alaska Native
    ○ Other

13) What best describes your marital status?
    ○ Married
    ○ Separated
    ○ Divorced
    ○ Never Married
<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>14) What best describes your highest completed level of education?</td>
<td>- Did not complete high school</td>
</tr>
<tr>
<td></td>
<td>- High school</td>
</tr>
<tr>
<td></td>
<td>- Some college</td>
</tr>
<tr>
<td></td>
<td>- Bachelor's degree</td>
</tr>
<tr>
<td></td>
<td>- Graduate degree</td>
</tr>
<tr>
<td>15) How long has it been since your child's last treatment?</td>
<td>- Less than a year</td>
</tr>
<tr>
<td></td>
<td>- Between 1 and 2 years</td>
</tr>
<tr>
<td></td>
<td>- Between 2 and 5 years</td>
</tr>
<tr>
<td></td>
<td>- Between 5 and 10 years</td>
</tr>
<tr>
<td></td>
<td>- Over 10 years</td>
</tr>
<tr>
<td>16) How many survivorship follow-up care appointments has your child</td>
<td>- None</td>
</tr>
<tr>
<td></td>
<td>- 1 or 2</td>
</tr>
<tr>
<td></td>
<td>- 3 or 4</td>
</tr>
<tr>
<td></td>
<td>- 5 or 6</td>
</tr>
<tr>
<td></td>
<td>- 7 or more</td>
</tr>
</tbody>
</table>
Childhood Cancer Survivorship

Below are questions about childhood cancer survivorship health. Thank you for your time!

1) How concerned are you that your child might develop a health problem later in life related to his/her previous treatment for cancer?
   - Not at all
   - A little bit
   - Moderately
   - Quite a bit
   - Extremely

2) How important do you think health behaviors like diet and exercise are to help prevent potential treatment-related health problems?
   - Not at all
   - A little bit
   - Moderately
   - Quite a bit
   - Extremely

3) Healthy diet in general
   - Not at all
   - A little bit
   - Moderately
   - Quite a bit
   - Extremely

4) Physical activity in general
   - Not at all
   - A little bit
   - Moderately
   - Quite a bit
   - Extremely

5) Better sleep
   - Not at all
   - A little bit
   - Moderately
   - Quite a bit
   - Extremely

6) Stress management
   - Not at all
   - A little bit
   - Moderately
   - Quite a bit
   - Extremely

7) Positive social support
   - Not at all
   - A little bit
   - Moderately
   - Quite a bit
   - Extremely

8) Please list on separate rows any health problems (chronic or life-threatening) that you think your child could get now or later in life because of his/her cancer or cancer treatment:

   ________________________________

Have you ever been told that your child might experience any of the following problems as a result of the cancer treatment that he/she received?

9) Heart problems (cardiac dysfunction)
   - Yes
   - No
   - Don’t know

10) Lung problems (pulmonary dysfunction)
    - Yes
    - No
    - Don’t know

11) A new cancer (subsequent neoplasm)
    - Yes
    - No
    - Don’t know

12) Bone weakness (low bone mineral density)
    - Yes
    - No
    - Don’t know

13) Cognitive issues (neuropsychological impairment)
    - Yes
    - No
    - Don’t know

14)
<table>
<thead>
<tr>
<th>Kidney problems (renal impairment)</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>15) Thyroid problems</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16) Fertility problems</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17) Diabetes or weight problems</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18) Vision or hearing problems</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
# Online Social Relationships

Below are some questions related to your online use. This means the time you spend connected to the internet, including social media, online shopping, browsing, and consuming news/entertainment/education.

On average, how many hours a week are you online (by phone, tablet, or computer)?

On average what percentage of that time is spent on childhood cancer related websites, social media sites or communicating online with others about childhood cancer?

<table>
<thead>
<tr>
<th>Percentage</th>
<th>0%</th>
<th>50%</th>
<th>100%</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*(Place a mark on the scale above)*

**To get information on anything related to childhood cancer, how often do you...**

<table>
<thead>
<tr>
<th>Activity</th>
<th>Never</th>
<th>Not currently, but at least once in the past</th>
<th>At least once a week</th>
<th>Once a day</th>
<th>2-3 times a day</th>
<th>4 or more times a day</th>
</tr>
</thead>
<tbody>
<tr>
<td>use google or another search engine?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>use social media (for example, Facebook, Instagram, Pinterest, Twitter, etc.)?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>use a hospital's website?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>use a medical information website (for example, WebMD)?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>use another website?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

**Social media are websites or apps that allow users to create personal profiles and share information. Examples are Facebook, Twitter, Instagram, and Google +. On social media, how often do you...**

<table>
<thead>
<tr>
<th>Activity</th>
<th>Never</th>
<th>Less than once a week</th>
<th>Less than once a day</th>
<th>Around once a day</th>
<th>Several times a day</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respond to a post by liking, loving, etc.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Post a message</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Comment on a post</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Send/receive a direct message</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

When you want to share information about your child's cancer or connect to other families on social media, which websites or apps do you use?
### Which of the following social media sites do you use?

<table>
<thead>
<tr>
<th>Social Media Site</th>
<th>Never</th>
<th>Used in past, now stopped</th>
<th>Once a month or less</th>
<th>At least once a week</th>
<th>Several times a week</th>
<th>Every day</th>
</tr>
</thead>
<tbody>
<tr>
<td>CaringBridge</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Facebook</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Google+</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Instagram</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Inspire</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Pinterest</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Tumblr</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Twitter</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Other</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

### On which social media sites have you met other childhood cancer parents?

<table>
<thead>
<tr>
<th>Social Media Site</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>CaringBridge</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Facebook</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Google+</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Instagram</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Inspire</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Pinterest</td>
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<tr>
<td>Tumblr</td>
<td>☐</td>
<td>☐</td>
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<tr>
<td>Twitter</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Other</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

### Which social media sites do you think are good for sharing and receiving reliable and high quality information on diet, physical activity, and other healthy behaviors?

<table>
<thead>
<tr>
<th>Social Media Site</th>
<th>Haven't used/don't know</th>
<th>Not at all</th>
<th>Somewhat good</th>
<th>Good</th>
<th>Extremely good</th>
</tr>
</thead>
<tbody>
<tr>
<td>CaringBridge</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
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<td>Facebook</td>
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</tr>
<tr>
<td>Google+</td>
<td>☐</td>
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<tr>
<td>Instagram</td>
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</tr>
<tr>
<td>Pinterest</td>
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<tr>
<td>Tumblr</td>
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<tr>
<td>Twitter</td>
<td>☐</td>
<td>☐</td>
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<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
Think about other childhood cancer parents who have been important to you throughout your child’s cancer treatment and survivorship. Have you developed a relationship through social media with any other childhood cancer parents?

How many other childhood cancer parents have you met and developed a relationship through social media?

Please number and list the initials of the other childhood cancer parents with whom you’ve developed a relationship over social media (up to 6). For example, if the two childhood cancer parents you developed a relationship with over social media are named John Doe and Amy Doe, you would put: 1) JD
2) AD

For your first childhood cancer parent online relationship, how close do you consider your relationship?

For your first online childhood cancer parent relationship, please check all the boxes for which you and this person are similar:

For your first online childhood cancer parent relationship, how many other online friends of yours does he/she know?

For your first online relationship, have you ever spoken on the phone or met in person?

For your second childhood cancer parent online relationship, how close do you consider your relationship?

For your second online childhood cancer parent relationship, please check all the boxes for which you and this person are similar:
## Online Social Support (continued)

Think about your experiences, relationships, and communications on social media websites or apps (for example, Facebook, Instagram, Pinterest, Twitter, etc.). How

1) I have people on social media who will listen to me when I need to talk...  
   - Never  
   - Rarely  
   - Sometimes  
   - Usually  
   - Always

2) I have people on social media to confide in or talk to about myself or my problems...  
   - Never  
   - Rarely  
   - Sometimes  
   - Usually  
   - Always

3) I have people on social media who make me feel appreciated...  
   - Never  
   - Rarely  
   - Sometimes  
   - Usually  
   - Always

4) I have people on social media to communicate with when I have a bad day...  
   - Never  
   - Rarely  
   - Sometimes  
   - Usually  
   - Always

5) I have people on social media to give me advice about a crisis if I need it...  
   - Never  
   - Rarely  
   - Sometimes  
   - Usually  
   - Always

6) I have people on social media to turn to for suggestions about how to deal with a problem...  
   - Never  
   - Rarely  
   - Sometimes  
   - Usually  
   - Always

7) I have people on social media to give me information if I need it...  
   - Never  
   - Rarely  
   - Sometimes  
   - Usually  
   - Always

8) On social media, I get useful advice about important things in life...  
   - Never  
   - Rarely  
   - Sometimes  
   - Usually  
   - Always

9) On social media I feel left out...  
   - Never  
   - Rarely  
   - Sometimes  
   - Usually  
   - Always
10) I feel that people on social media barely know me... ○ Never
○ Rarely
○ Sometimes
○ Usually
○ Always

11) I feel isolated from the people I see on social media...
○ Never
○ Rarely
○ Sometimes
○ Usually
○ Always

12) I feel that when I interact on social media with others I have a hard time connecting...
○ Never
○ Rarely
○ Sometimes
○ Usually
○ Always

---

Now think about the people with whom you interact regularly. This can include your family, friends, colleagues, and other personal contacts...

13) I have someone who will listen to me when I need to talk...
○ Never
○ Rarely
○ Sometimes
○ Usually
○ Always

14) I have someone to confide in or talk to about myself or my problems...
○ Never
○ Rarely
○ Sometimes
○ Usually
○ Always

15) I have someone who make me feel appreciated...
○ Never
○ Rarely
○ Sometimes
○ Usually
○ Always

16) I have someone to talk with when I have a bad day...
○ Never
○ Rarely
○ Sometimes
○ Usually
○ Always

17) I have someone to give me advice about a crisis if I need it...
○ Never
○ Rarely
○ Sometimes
○ Usually
○ Always

18) I have someone to turn to for suggestions about how to deal with a problem...
○ Never
○ Rarely
○ Sometimes
○ Usually
○ Always
19) I have someone to give me information if I need it...
   - Never
   - Rarely
   - Sometimes
   - Usually
   - Always

20) I get useful advice about important things in life...
   - Never
   - Rarely
   - Sometimes
   - Usually
   - Always

21) I feel left out...
   - Never
   - Rarely
   - Sometimes
   - Usually
   - Always

22) I feel that people barely know me...
   - Never
   - Rarely
   - Sometimes
   - Usually
   - Always

23) I feel isolated from others...
   - Never
   - Rarely
   - Sometimes
   - Usually
   - Always

24) I feel that people are around me but not with me...
   - Never
   - Rarely
   - Sometimes
   - Usually
   - Always
Depression and Anxiety

Please respond to each question or statement by marking one box per row.

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) I felt fearful...</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>2) I found it hard to focus on anything other than my anxiety</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>3) My worries overwhelmed me...</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>4) I felt uneasy...</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>5) I felt worthless...</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>6) I felt helpless...</td>
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<td>7) I felt depressed...</td>
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<td>8) I felt hopeless...</td>
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APPENDIX B: Semi-structured Interview Guide

Introduction: My colleagues and I are doing a study to learn more about the role of social support in survivorship care for parents of young childhood cancer survivors. Understanding parents’ perceptions of survivor health risks, preventive health information, and social support are important for designing programs that can improve quality of life and long-term health for childhood cancer survivors. The information gathered in this study will help us and others find better ways to support families like yours.

I would like to ask you questions about topics such as the transition from treatment into survivorship, dealing with late effects of treatment, follow-up care, and your connection with other families affected by cancer. But before we begin, do you have any questions or concerns?

Current survivorship caregiving experiences

1) How are you and your survivor are doing right now?

Prompts: Was treatment challenging for you, your family, or child? What was it like to end treatment? Do you think the doctors and healthcare team did a good job transitioning you and your child into survivorship?

2) Can you recall being counseled on survivorship (late effects, follow-up care, long-term risks, continuing challenges) by your healthcare team?

Prompts: Can you tell me who counseled you and what it was like? Did you find it helpful? Were you given any survivorship-related materials or resources?

3) Are you aware of any survivorship-related programs offered by your hospital or healthcare provider. Have you been involved in any of these programs?

Prompts: How do you feel about the survivorship-related programs and resources that are available? Does your spouse feel differently? What do you wish your hospital had for survivors that they don’t now?

4) Have you looked for any survivorship resources online? Social media? Apps? What do you wish was available online/mobile apps?

Survivorship Health Risks and Prevention

4) Tell me about the long-term health risks your child faces because of cancer treatment.

Prompts: Are you concerned about any particular long-term health risks? What concerns you the most? Where do you go to find out more about long-term health risks? Has your child expressed any concerns about their post-treatment health?

5) Tell me how you feel about the level of information you’ve been given so far on the long-term health risks your child faces?

Prompts: Would you like to know more? What would be the best way to convey this information? Are there things you’d rather not know or talk about?
6) Has any doctor or nurse talked with you about preventive health behaviors like diet or exercise that can lower long-term survivorship health risks? Can you tell me about this experience?

Prompts: Would you like to know more? What do you wish they had told you? What sort of programs or resources for prevention would you like to see?

7) Where do you look for preventive health information?

Prompts: Are there any sources of information like books or websites or people that you trust for preventive health information? If you had a question or wanted to start a new health practice, where would you turn for help?

8) Do you feel like your family is motivated to practice preventive health behaviors like healthy diet and regular exercise?

Prompts: What are the biggest barriers for your family in practicing preventive health behaviors for cancer survivors? What are the easiest health behaviors to engage in and which are the hardest? What kinds of programs or resources would you like to see to help families like yours engage in preventive health behaviors?

Social Support

9) Who are the most important sources of emotional and informational support for childhood cancer survivorship? How have you found other parents of childhood cancer survivors? Did your docs ever talk about other families like yours/ connecting you? Have these relationships been important to you? Tell me how they’ve helped or been a burden on your childhood cancer journey.

10) Tell me about finding other parents of childhood cancer survivors online. Where did you start? Tell me about the journey online up until now.

11) Tell me a story about a particularly positive online interaction or relationship with another childhood cancer parent.

12) Tell me a story about a particularly negative online interaction or relationship with another childhood cancer parent.

13) Tell me about the cancer-related information you give and receive online to other childhood cancer parents. Where do you go online for survivorship-related health information? Who would you ask?

14) Tell me about your daily social media routine. Which sites do you like the most and why?

15) If you could design your own ideal online childhood cancer support group, what would it look like? How big would it be? What factors would be most important in sorting who’s in the group (diagnosis, parent age, child age, parent gender, child gender, geography, stage in treatment/survivorship, cultural factors [religion, political views], parent education level)? What resources would you like in this group (information, therapist, dietitian, health coach, nurse)? When would the group start – during treatment or after? How long would the group go for? Would it be a mobile app or mostly web-based? Any other special features?
REFERENCES


75. Brady, E., Segar, J., and Sanders, C. You get to know the people and whether they’re talking sense or not: Negotiating trust on health-related forums, *Social Science & Medicine* (2016).


