Sharing Illness Experiences on Twitter: Conversations of Parents with Children Diagnosed with Cancer

by

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Abstract

The purpose of this research study is to identify the key themes of tweets posted by parents of children diagnosed with cancer, as well as to identify the reported motivations and benefits for using Twitter as a means to share information related to a child’s cancer experience. Tweets were collected from 17 twitter accounts that belong to parents of children diagnosed with cancer, and e-mail interviews were conducted with 5 of the parents. Savolainen’s framework of everyday information practice was applied in understanding the key themes of tweets posted by the parents recruited for this study. The themes include – social support and coping, casual conversations, sharing childhood cancer related facts, promoting campaigns and fundraising, raising awareness, and providing updates. The findings of this study added new information to existing research that could potentially lead to the development of a theory of online health communication during illness.
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And lastly, I am grateful for the two wonderful angels who watch over me always. My sweet little Samara, and Abbu - my father. You two are the reason this thesis started and eventually got completed. I didn’t give up. And I never will.
Dedication

To my angel Samara – the light of my life.

To Abbu – I wish you were here to read this. Everything I write is for you.

To the children, whose parents so graciously allowed me to study their tweets. And to the parents.
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Chapter 1
Introduction

A child diagnosed with cancer changes a family’s lives forever. Parents caring for a child diagnosed with cancer face insurmountable challenges filled with uncertainty and anxiety, leading to an ongoing experience of psychosocial distress (Björk, Wiebe, & Hallström, 2005). Parents often feel that they lose their “normal” way of life, and find themselves adapting to unexpected changes and re-prioritizing life in an attempt to define a new “normal” way of living (Earle, Clarke, Eiser, & Sheppard, 2007).

Cancer continues to be the leading disease-related cause of death among children (Canadian Cancer Society, 2011). The American Cancer Society reports that in 2014, an estimated 15,780 new cases of childhood cancer will be diagnosed in America, and 1960 deaths from cancer will occur among children and adolescents aged birth to 19 years (Ward, et al., 2014). The effort to treat and cure cancer however continues to focus primarily and rightfully on the physical effects of the disease as well as finding means to treat physical symptoms (Jacobsen, Holland, & Steensma, 2012). Despite the recent increased possibility of survival and hope, the chaos and emotional distress that arises from a child’s diagnosis of cancer suggests the need to study and understand the various psychosocial needs of a family caring for a child following a diagnosis of cancer. A recent series of workshops held by the Institute of Medicine (IOM) summarized the needs and challenges within the area of information management in cancer care and suggested that patient engagement can be improved by empowering the patients to drive disruptive innovation within their own health care experience (National Cancer Policy Forum, 2012).

There are existing studies that examine the viewpoint of breast cancer patients and survivors about their experience with using online support groups to exchange information (Høybye et al., 2005), or patients of esophageal cancer using social media platforms to connect with individuals with similar health circumstances (Kaplan, 2012). These studies have contributed to the overall understanding of information needs and challenges faced by cancer patients. The studies have also attempted to explain the phenomenon of online communication among cancer patients. In the field of pediatric cancer, a study of narratives published in personal blogs maintained by parents of children diagnosed with cancer, as well as interactions among the author and
commenters on these blogs, has suggested a need for further research on content published online by parents of children diagnosed with cancer (Heilferty, 2009). Built upon these recommendations of research on the usage of social media and social networking platforms in health communication, a qualitative analysis of tweets posted by parents of children diagnosed with cancer will add new knowledge about the role or Twitter within the childhood cancer community.

Using Twitter as a social-media and micro-blogging tool to share information is a relatively new phenomenon - especially within the realm of sharing illness experiences. Twitter was introduced in 2007 with the mission to “give everyone the power to create and share ideas and information instantly, without barriers” (Twitter, 2014). Twitter has grown rapidly over the years and currently has over 241 million monthly active users, and approximately 500 million Tweets posted per day. Despite its rapid growth, using Twitter as an online illness narrative tool – as used by parents of children diagnosed with cancer – is a relatively unexplored area of research. Using social media platforms like Twitter is viewed by health care and communication researchers as a tool to empower patients and their families in managing their activities related to seeking and exchanging information (Wiener et al., 2012; Hawn, 2009). Twitter provides a unique and time-effective way of communicating. In comparison to regular blogging, micro-blogging encourages shorter posts which require less thought investment for content generation and subsequently less time (Java et al., 2007; Scanfeld et al., 2010). The frequency of updates can also be significantly higher than regular blogging – thereby generating increasing interest in the already expanding area of online health information research. Rather than static profiles used for self identification, posting and exchanging tweets with other users establishes a representation of identity on Twitter (Marwick & boyd, 2011). The ability to represent identity through conversation in a seemingly anonymous environment has not yet been researched to a significant extent. Twitter, as used specifically within the cancer community, has evolved towards creating a powerful online network of support and health information exchange (Butcher, 2009; Sugawara et al., 2012; Scanfeld et al., 2010). Understanding and analyzing the narratives shared by parents of children diagnosed with cancer online through social networking platforms like Twitter has the potential to play a role in enhancing the patient-provider relationship within pediatric oncology, and also to contribute significantly towards existing research in the fields of nursing and social work by providing key information towards developing a theory of online
communication as experienced when a child is diagnosed with cancer (Wiener et al., 2012; Hawn, 2009; Heilferty, 2009). Identifying the dominant themes of tweets posted by parents of children diagnosed with cancer can lead towards an overall understanding of the content that forms narratives on Twitter.

Facing the possibility of losing a child following the child’s diagnosis with cancer, parents immediately start depending on information about the child’s condition, and rely on various support services for knowledge that can help reduce the chaos that is now their “normal.” Access to information and support not only provide parents with a feeling of control, but also helps in reaching a meaningful understanding of their overall circumstances (Björk, Wiebe, & Hallström, 2005; Fletcher & Clarke, 2003). In this research study the researcher has investigated the phenomenon of parents of children diagnosed with cancer posting Tweets related to their child’s cancer experience, as well as using their Twitter network to share and exchange personal perspectives and thoughts.

Although the researcher’s personal experience with using social media while caring for a child diagnosed with cancer provides a unique perspective on the subject matter of this study, potential personal bias was addressed by maintaining reflexivity throughout data collection and analysis activities in order to ensure ethical neutrality (Luker, 2008). The researcher has provided suggestions for future research in the area of examining the use of Twitter and other social media platforms that can impact the overall health care experience of families following a child’s cancer diagnosis.

1.1 Research questions

Two key research questions were identified for this research study.

Question 1: What are the key themes of conversation observed on Twitter among parents with children diagnosed with cancer?

Question 2: What are the reported benefits and motivations for using Twitter for conversations about a child’s cancer experience?
These questions were chosen while maintaining a focus on the overall approach of understanding perspectives of parents of children diagnosed with cancer as expressed through narratives and conversations online with a view towards the potential role played by these perspectives in creating an enhanced health care and psychosocial support experience within pediatric oncology. This study intends to add to the existing body of literature related to patient narratives published on social media, and subsequently fill a gap by contributing knowledge about the specific themes of conversations observed on Twitter among parents of children diagnosed with cancer, and about the reported benefits and motivation of using Twitter for these conversations.

1.2 Chapter summaries

Chapter 2 is a literature review that situates this research study within relevant existing research. Chapter 3 describes the research methodology designed for this study by describing participant recruitment, data collection, analysis and how the data was synthesized. Chapter 4 describes the results of this research study. Chapter 5 entails a discussion based on the results, and provides suggestions for future research. Chapter 6 provides brief concluding remarks.
Chapter 2
Literature Review

This research study is situated within existing research about using social media platforms to enhance patient and family centered health care experience. The following sections outline the importance of a patient and family centered approach in pediatric health care, and how patients and their families use the internet to communicate and share information about personal health experiences. The role of social media within online health communication has been demonstrated by providing examples of existing research studies, with a focus on existing studies related to analyzing Twitter for health care research.

2.1 Patient and family centered care in pediatrics

In pediatric health care, the patient is a child. The child’s family is his or her foundation of strength and support. Parents and family members depend on knowledge and information from individuals in similar circumstances in addition to support from health care professionals during the extremely difficult and emotionally strenuous experience of caring for a severely ill child (Holm et al., 2003; Eichner, 2003). Continued research on outcomes and implementation of a patient and family-centered approach within pediatric health care delivery is therefore very important.

2.2 Patient generated content on the internet

In recent times, the internet has become an important source for health information and social support for patients and their families. Patients and family members are not only using the internet to search for health information, but also to create and share their own content (Burton, 2008; Bos, et al; 2008). There are multiple studies indicating a need for research that leads to theoretical, methodical and scientific basis to understand the impact of online accounts of personal experiences shared by patients and their family members (Ziebland, 2012; Hawn, 2009; Fernandez-Luque & Grajales, 2009). Personal health related information, experiences, advice, and perspectives shared by patients and their loved ones are collectively considered as patient generated content. Such content is accessible not only by other patients and family members but
also by medical and support professionals (Hawn, 2009), depending on the type of web platform used to publish patient generated content.

2.3 The role of social media in sharing health information online

Social media provides one of many options to publish patient generated content. Some social media platforms require users to log in to a closed environment only available to registered members. Some platforms are viewable by anyone willing to read or participate. Among some of the websites used by patients and families for health related social interactions are Facebook, Twitter, YouTube, CarePages, CaringBridge, Pinterest, blogs, and online discussion forums like parenting communities on BabyCenter.

This study on the usage of Twitter by parents of children diagnosed with cancer has been informed and guided by existing studies that explored a varied range of social media platforms used by patients to share their personal experience. A study by Fernandez-Luque and collaborators (2009) examined content shared on YouTube by Multiple Sclerosis patients as well as their interaction with commenters and other patients who posted videos. A study by Robillard and collaborators (2013) observed tweets posted by the aging population discussing dementia to examine the sources of information that are promoted through social media platforms and identified the dominant themes of discussion related to dementia on Twitter. Social media websites have also been viewed as crowdsourcing platforms where clinicians and patients can collaborate to manage disease outbreak and predict pandemics (Ritterman et al., 2009; Purvis, 2012), as well as a space where cancer patients can collectively identify treatment options through finding information about clinical trials (Chretien et al., 2011). A case study conducted in the early days of online support groups revealed that a simple online mailing list for breast cancer survivors played a crucial role in easing the social isolation following a cancer diagnosis (Høybye et al., 2005). A Facebook group has been successfully used to meet the informational needs of patients and survivors of esophageal cancer who were geographically dispersed or were not comfortable or willing to use phone, e-mail or fax based communication (Kaplan, 2012).

The National Children’s Cancer Society in the United States hosts a Facebook page that engages users through discussions and comments from childhood cancer survivors and their families (Kaplan, 2010). They also partner with CaringBridge to provide a free service where people can
create personalized profiles with text and images, and interact within a closed social media environment for illness experiences. Social media platforms like Pinterest provide opportunities to publish content related to childhood cancer advocacy by promoting inspirational messages and vision boards for children living with cancer as well as their friends and loved ones (Never Ever Give Up, 2013).

Following recommendations set forth by an IOM report (Jacobsen, Holland, & Steensma, 2012) focusing on the overall psychosocial affects of cancer on the patient as well as the family, a recent research study related to the usage of blogs by parents of children diagnosed with cancer examined how parents foster “peer” relationships through illness narratives on the internet (Heilferty, 2009). The consequences of a parent blogging about the child’s cancer experience were found to be both positive and negative, as stated in the research findings. The positive consequences included uncertainty management, identity evolution, integration of illness events into family life, stress management, enhanced communication of events, feelings and responses to and from the audience of the blogs, establishment of legacy, improved relationships and diminished isolation. The negative consequences of blogging included hurt feelings caused by differences in opinion between the reader and author of the blog, social isolation, skewed perception of readers due to viewing the overall experience of caring for a child with cancer only from the perspective of the author of a particular blog, and lastly, taking time away from loved ones which can lead to strained relationships. While the research findings suggested that reading and incorporating illness blogs into health care can enhance the relationships between the patient and the health care provider in the context of pediatric oncology, an increasing need was revealed for further investigation of how parents share and exchange information online through different “computer-mediated” platforms when their child is diagnosed with cancer. Heilferty’s study (2009) also suggested the possibility of developing a theory of online communication during illness based on future research focused on other online media used by parents of children diagnosed with cancer.

2.4 Analyzing tweets for health care research

The purpose of this study is to establish the dominant themes of tweets posted by parents of children diagnosed with cancer, as well as establish the underlying motivations for choosing to share their personal experience and perspectives using Twitter, versus other social media
platforms, situating this understanding within the existing body of literature about research on the multifaceted discussion of patient generated content on the internet. Examining tweets with the purpose of establishing empirical evidence about online health communication has proven to lead towards practical and important research findings. A group of health care analytics experts formed Symplur, with the intention of helping healthcare business find value in online health communication and patient generated data on the internet (Utengen, 2012). Symplur archives and mines data collected from online health conversations that take place in public social media websites. As an example, by conducting big data analysis on data archived over a 22 month timeline starting in September 2010 involving about 100 million health care tweets retrieved from about 2,000 different health communities within Twitter, Symplur dynamically monitored the progression of patient centric topics on Twitter as well as topics that are related to professionals or health care service providers. The result of this study revealed the gradual yet steady and significant rise of patient-centric content on Twitter compared to content generated by professionals or providers. As the popularity of social media websites for health communication grew over the past decade, the role it played within cancer survivorship and treatment notably changed the way cancer patients seek information about their health condition as well as how they foster social support networks based on shared experiences and online interactions (Murthy et al., 2011; Høybye et al., 2005). Symplur also provides powerful visualizations of the social networks and connections based on big data analysis of millions of health related Tweets (Utengen, 2012). In doing so, they have determined the types of users who are engaged in conversation using Twitter hashtag #BCSM which stands for Breast Cancer Social Media. They were able to visualize the types of user names chosen by individuals using this hashtag as well as information such as the frequency of posts within the selected data sample. By viewing network visualizations of such communities over time, they were able to document the phenomenon of users being pulled into conversations and the choices they made in terms of users and topics to interact with.

2.5 Summary

In summary, a patient and family centered approach in pediatric health care is important as parents are involved in making key decisions about their child’s health care and advocating for the best interest of the child. Parents and family members are turning to the internet more and
more to find information about their child’s health care, and also actively sharing a vast amount of information on the internet. Twitter is one of many online platforms used by parents of children diagnosed with cancer to share information related to their child’s cancer experience. Existing research in the area of online health communication suggests that identifying the key themes of tweets posted by parents of children diagnosed with cancer, and understanding the motivations and benefits reported by parents for choosing Twitter as a tool to generate content about their child’s cancer experience can contribute towards creating new knowledge that can play a role in enhancing the overall patient and family centered approach in pediatric cancer care.
Chapter 3  
Research Methodology

3 Research methodology

A qualitative mixed-method approach was applied in collecting and analyzing data for this research study. An inductive content analysis of Tweets collected from accounts belonging to parents of children diagnosed with cancer was used to understand conversations taking place on Twitter. A qualitative thematic analysis of email interviews conducted with the parents who own the Twitter accounts provided a deeper insight into the purpose and motivations of these conversations.

3.1 Participants

All participants for this study were recruited on Twitter. The criteria for participating in this research study was as follows:

i. Parent of a (living or deceased) child diagnosed with cancer at any age younger than 20.
ii. Currently owns an active Twitter account and has tweeted at least once within the past 7 days at the time of recruitment.
iii. Selected Twitter account maybe personal or representing charity organization in memory of deceased child. In case of organization, the parent must identify that he/she is the one Tweeting on behalf of the organization.

Although childhood cancer is considered within the age range of newborns to 14 years old, adolescents are also typically treated by pediatric oncologists. Therefore this study considered the age range of children with pediatric cancer up to the age of 19 (Cancer.net, 2012; American Cancer Society, 2013; Childhood Cancer Canada, 2011).

3.1.1 Recruitment

An initial search for hash tag #childhoodcancer was used to identify a list of current tweets on the topic. The tweets retrieved by this search were examined to determine Twitter accounts that belong to parents of children diagnosed with cancer. Self-identification information provided on each Twitter account was used to identify accounts of parents with children diagnosed with
cancer. A publicly viewable recruitment tweet (Appendix A) was sent to the initially identified account holders which included a link to an introductory message (Appendix B) as well as a web-based informed consent form (Appendix C). The introductory message explained the details of the research project and outlined expectations of potential participants. The purpose of the informed consent form was to meet requirements from the ethics review board to receive acknowledgment from the invited participants and to confirm their interest in participating in this research study.

Participants were asked to provide consent for the publicly available content published on their Twitter account to be analyzed for the purposes of this research study. Although the content was publicly available, consent was requested in order to ensure a trusting relationship with the participants in the context of the sensitive nature of this study. Participants were also invited to an optional email interview, for which they were asked to provide an email address for further communication. The federal research ethics guidelines, the Tri-council policy statement: Ethical conduct for research involving humans, 2nd edition (TCPS -2) Article 10.3 provides research ethics guidelines for activities involving direct interaction with participants, reasonable expectation of privacy, identifiability, and sensitivity of topic (Panel on research ethics, 2012). Given the sensitive nature of the topic of this research study, the chosen method of direct interaction with participants over email, as well as an intention to use direct quotes and attributions that could potentially be identifiable and traceable made it essential to clearly inform participants of the steps taken to protect their privacy and identity through a formal process of obtaining consent. Parents of children who are currently in treatment for cancer, or have recently undergone treatment may not be willing to take time away from their child for traditional face-to-face or telephone interviews, and therefore email was chosen as a sensitive way of interviewing for the purposes of this research project. A set of open ended questions was sent to the interviewees in an email (Appendix D). This opened up a path for further conversations and clarifications when needed. Sending questions in stages (Bampton & Cowton, 2002) provided an interactive environment, and allowed the interviewee to respond at their own convenience.

A total of 56 recruitment tweets were sent between February 2013 and August 2013, and 17 accounts were identified for analysis in this study. These accounts belonged to 15 individuals, as 2 of the recruited individuals owned 2 accounts each – one personal account, and one account in
memory of their deceased child. These individuals provided consent to use tweets from both accounts. In total, therefore, 15 individuals agreed to participate in the study and provided informed consent to analyze their tweets from a total of 17 Twitter accounts.

Although 13 of the 15 recruited individuals agreed to participate in email interviews, complete responses were received from 5 individuals, leading to an approximate response rate (Jones & Pitt, 1999) of 38%.

3.2 Data collection

As each participant viewed and signed the web based informed consent form, tweets were collected from the corresponding Twitter account for analysis. The website randomizer.org was used to generate 4 random timeframes consisting of a one-week duration within each of the past 4 months starting from the month in which informed consent was received from the participant. For example, if a participant viewed and signed the informed consent form in October, the randomizer website was used to identify a random one week period in June, July, August, and September. All tweets posted within the 4 selected weeks were collected for analysis. Web-based Twitter analytics tool Twitonomy (http://www.twitonomy.com/) was used to retrieve tweets from the recruited participants for those week-long timeframes. This tool provided the means to download a snapshot of tweets from each user within the specified time frames directly into Excel files. Each time a participant signed up on the informed consent webpage, a snapshot of tweets was taken. Each participant was assigned a “Person ID” and tweets were stored in spreadsheets labeled with this ID only in order to remove identifiable information. The data stored in these spreadsheets included the Date/Time of the tweet, the text of the tweets, and whether this is a retweet.

In addition to the Person ID for each participant, each tweet was also assigned an ID number. The number of extracted tweets varied for each participant based on how often or infrequently they tweeted during the selected date ranges. The highest number of tweets obtained from an individual account was 3,248 over the 4 selected weeks, while the lowest number of tweets obtained from an account for the selected time frames was 132. The complete set of tweets was archived in individual spreadsheets per Twitter user. Based on examples from similar qualitative studies of Twitter data, the randomizer.org website was used to identify 100 tweets at random
(Lalonde, 2011; Robillard et al., 2013) from each account for the purposes of detailed content analysis.

3.2.1 Designing and conducting e-mail interviews

The purpose of collecting input from participants through interviews was to fully understand the context of their Twitter account and tweeting experience. Each participant that agreed to participate in an interview was contacted individually, and was interviewed through email conversations.

The participants were provided an overview of the study, confidentiality information, as well as a detailed description of the interview in the initial introductory website. Participants were also asked to sign an Informed Consent form that detailed the e-mail interview process. A set of open ended questions was sent to the interviewees in a single e-mail after they provided informed consent and agreed to participate (Bampton & Cowton, 2002; Mccoyd & Kerson, 2006; Meho, 2006). This approach familiarized the participants with expectations about the interview ahead of viewing the interview questions, and allowed the interviewee to respond at their own convenience.

The questions in the e-mail interview were designed such that the participant is able to tell a story. In order to ensure reflexivity in addressing the researcher’s personal experience with the subject matter, the questions were stated in a way that provided opportunity for open ended answers that were intended to be interpreted subjectively. This approach mitigated an expectation of objective answers that could potentially be influenced by the researcher’s personal experience (Luker, 2008, p157). The intention was to analyze responses received from e-mail interviews in a reflexive way that transcends personal familiarity with the subject matter. The questions therefore were designed to ensure that responses which may be perceived as natural and familiar by the researcher were captured along with what appeared to be “unusual” or unexpected (Luker, 2008, p157). The e-mail was divided into 3 sections. The first section asked questions related to the participant’s motivations for choosing Twitter as a platform to share information about the child’s cancer journey. The second section was more detailed, and asked probing questions about the participant’s overall experience with Twitter. The last section was left open for any additional comments or information the participant may choose to provide.
While all questions were open-ended, some of them provided example choices that may lead the participant towards sharing further details. Responses received from these interviews were analyzed along with a close reading of a selection of tweets from each Twitter feed to obtain a richer understanding of the context of the research questions.

As each participant responded to the e-mail interview, the text of the e-mail response was saved in individual word documents. Names and email addresses were removed in order to make the response un-identifiable for the purpose of analysis and dissemination of research findings. The “Person ID” assigned initially to all recruited participants was used to link the email interview transcripts to the tweets collected from each participant’s Twitter account.

### 3.3 Data analysis

Data analysis was conducted in two phases separated by the source of the collected data. The first phase of analysis involved close reading and content analysis of tweets retrieved through Twittonomy followed by analyzing the email interview responses.

#### 3.3.1 Qualitative content analysis of Tweets and e-mail interviews

The first phase of analysis involved Tweets retrieved through Twittonomy. A hundred tweets per participant were methodically selected for detailed qualitative content analysis. Each Twitter account recruited for this study was viewed as an individual case. Content analysis techniques were applied on a case by case basis to study the phenomenon of “how” and “what” conversations are taking place on each Twitter feed (Eisenhardt, 1989; Small, 2009). Content from the Twitter feeds were coded to identify high level categories without identifying frequencies of occurrence. The purpose of analysis was to subjectively reflect the content of conversations published on the selected Twitter accounts. An inductive approach to coding was used as there were no existing relevant studies involving the role of Twitter in the field of Pediatric Oncology that could potentially provide a substantial framework or list of codes for qualitative analysis. Acknowledging the open-ended and flexible characteristics of content analysis as a research method, a close reading of the selected Tweets from each account was used to contextualize the findings of the overall analysis (Thomas, 1994; Elo & Kyngäsv, 2008). The purpose of applying a close reading approach is to look beyond Twitter as merely the medium of conversation – rather treat it as a platform seamlessly integrated in an environment
where parents of children diagnosed with cancer freely share thoughts and knowledge while seeking support from each other. Although close reading does not aim to produce an individual true meaning of the text, it allows the reader to look beyond the face value of text through a repeated process of demolishing the text and reconstructing it based on a higher understanding or context of the represented conversations (Looy & Baetens, 2003 : 7-10). Close readings of reflective narratives of patients has been suggested to be a powerful tool that can allow health care professionals to “reach out and join their patients in illness” and to recognize the personal journeys of the patients (Charon, 2001). Twitter conversations of parents of children diagnosed with cancer can certainly be viewed as personal reflections of their experience or as illness narratives. A close reading of these narratives can therefore assist in bridging the gap between physicians, patients and society – eventually leading to a path for a deeper understanding of these conversations to identify opportunities for a “respectful, empathic, and nourishing” health care environment.

Following analysis and coding of Tweets, the e-mail interviews were analyzed with a similar approach in the second phase of analysis. The responses received from the e-mail interviews were examined separately from the tweets to obtain a richer understanding of the initial content analysis labels and categorization, and to identify potential motivational factors behind using a social media platform like Twitter. The interviews were analyzed by reading the answers to the questions directly as communicated by the participants. The coding scheme used for the interviews was different from the coding scheme applied to the Tweets, but were contextually similar.

3.3.2 Coding

The coding process for tweets as well as the e-mail interview response was conducted in 3 stages. The first stage involved creating an initial “start-list” of codes prior to reviewing the collected Tweets and e-mail interviews. The second stage was an in-depth open coding activity (Miles & Huberman, 1994). The third and final stage of coding was to identify patterns which led to answering the research question.
3.3.2.1 Analyzing tweets

Stage 1 - Creating a “start-list” of codes

The start-list used for analyzing Tweets was inspired by basic characteristics of the Twitter platform, and the proposed research questions. It may be noted that the start list does not represent a formal framework; rather the list was used as general guidelines or as a starting point to categorize key concepts throughout the content analysis process. The interpretations of the context of categories were subjective (Kracauer, 1952-1953), however, close reading of the retrieved tweets assisted in placing each piece of information within a comprehensible background narrative or story line. Tweets that appeared to be memorable or significant in some way were saved for reference during analysis and explanation.

<table>
<thead>
<tr>
<th>Code Label</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>RT</td>
<td>Identifies whether this message has been re-tweeted by the user.</td>
</tr>
<tr>
<td>Picture of child</td>
<td>This field identifies whether a picture of the child has been shared within the Tweet.</td>
</tr>
<tr>
<td>Link shared</td>
<td>This field identifies whether a link has been shared within the Tweet.</td>
</tr>
<tr>
<td>Mentioning a person</td>
<td>This field identifies whether a Tweet mentions a person using the Twitter @ sign. This signifies the Tweet is trying to draw someone's attention.</td>
</tr>
<tr>
<td>Providing update</td>
<td>This field identifies whether this Tweet is providing an update about the child's condition to friends and family.</td>
</tr>
<tr>
<td>Cancer related hashtag</td>
<td>This field identifies whether a cancer related hashtag has been used within the Tweet.</td>
</tr>
</tbody>
</table>

Table 1 Tweet analysis start-list
Table 1 displays the start-list of codes applied while categorizing tweets from the recruited participants. This table also provides a brief explanation of the codes.

**Stage 2 - Open coding**

Each set of tweets was read closely in order to get an overall understanding of the background story and context of each recruited participant’s tweeting experience related to the child’s cancer journey. An inductive coding technique was applied in order to expand the start-list of codes and derive new codes based on the context, significant feelings expressed, events described, thoughts communicated, interactions between Twitter users, and meaning exposed through the process of reading and re-reading the selected tweets (Strauss & Corbin, 1998; Miles & Huberman, 1994). None of the initial codes were deleted, and none of the initial meanings of the codes were changed. Only new codes were added to the list. The coding exercise was conducted by a single coder. In consideration for validity and reliability of the applied codes, sample sets from the coded data were reviewed by the research supervisors at the end of the initial coding iteration. After completing this initial iteration of coding, all tweets were re-read to ensure that each tweet was categorized with the newly added codes. This process ensured reflexivity in mitigating potential bias due to the researcher’s personal experience in the subject matter by allowing codes to emerge through repeating the activity of reading tweets and categorizing (Kirby & Mcenna, 1989, p32). The additional reviews conducted by the research supervisors were viewed as a checkpoint to help guard against reflection of personal bias.

Appendix F describes the complete list of codes following the final iteration of coding. Codes were defined prior to assigning them to tweets so that a single coder could consistently apply the codes repeatedly (Miles & Huberman, 1994). Each Tweet was read and labeled with one or more codes listed in Table 1.

Code labels were assigned directly on the Excel Spreadsheets that were used to store the selected tweets. A field called ‘note’ was used store comments and noteworthy characteristics of tweets that were found to be memorable or significant to the analysis. This field was used to keep a note or description about something unusual or interesting about the particular tweet.
The complete list of codes at the end of the open coding stage therefore included the initial start-list of codes as well as codes that emerged through iterative close reading of the selected tweets that led to a deeper familiarity and understanding of the context and background of the content.

*Stage 3: Pattern coding – identifying themes*

To reach an integrated scheme of understanding leading towards a potential description of the observed phenomenon, the complete set of coded data was revisited in the final stage. Overarching themes were identified in this stage of coding based on the organized and previously coded data. The research questions as well as the definitions of the codes from stage 2 were used for guidance at all times during this final stage of coding in identifying patterns within the chunks of data that had already been coded (Miles & Huberman, 1994). The list of codes from stage 2 was the driving force for identifying themes, and the “note” field was used to obtain context or enhanced understanding when needed. In the final stage of coding, the complete set of coded data was examined carefully as a whole to identify themes and potential storylines that may have emerged through analysis.

A data-based “editing” style of analysis, as described by Miller and Crabtree (1999) was taken in contextualizing the final stage of coding. The chunks of data coded in the second stage were contextualized using the category code. In the final stage of coding, these categories were used to reorganize the data into meaningful themes. In order to maintain integrity of the research method, the content of Tweets were decontextualized by considering only the codes while identifying themes without viewing the content which had been coded already. The integrity of the themes was recontextualized by viewing each theme one at a time and probing further to ensure content was not missed or mis-aligned with themes. At this step, sample Tweets were assigned to each high level theme (Tesch, 1991; Crabtree & Miller, 1999; Miles & Huberman, 1994).
3.3.2.2 Analyzing e-mail interviews

Stage 1: Creating a “start-list” of codes

The start list of codes for the e-mail interviews was chosen with the purpose of aligning codes to the questions asked within the interview. The start-list therefore was guided completely by the questions asked. The start-list of codes for e-mail interviews is shown in Appendix G.

Stage 2: Open coding – identifying themes

Each e-mail interview response was coded using the start-list. Following the first iteration of coding each email interview response two new codes were added in order to allow overarching themes to emerge from the data. The following table shows the two additional codes added to the start list described in stage 1.

<table>
<thead>
<tr>
<th>Code Label</th>
<th>Interview Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive impact of Tweeting</td>
<td>Identifying responses that alludes to the positive impacts experienced</td>
</tr>
<tr>
<td>Did not find Twitter to be useful</td>
<td>Discussions related to Twitter not being useful or Twitter having a negative impact in overall experience while coping with child’s cancer experience.</td>
</tr>
</tbody>
</table>

Table 2 E-mail interview analysis – additional codes

Stage 3: Pattern coding – identifying themes

The final stage of email interview analysis involved identifying overarching themes within the coded data. The email interview data was considered as individual quotes, and the coded data was essentially a set of coded quotes. Overarching themes were derived from the coded quotes.

3.4 Data synthesis: Answering research questions

Data synthesis for this study was conducted following Spradley’s 9 dimensions of descriptive observation in social situations (Spradley, 1980). The phenomenon of parents of children
diagnosed with cancer using Twitter to share glimpses of their family’s experience with the child’s illness was mapped through the 9 dimensions suggested by Spradley’s framework.

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Mapping dimensions</th>
<th>Analysis activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>SPACE</td>
<td>Childhood cancer community on Twitter</td>
<td>Harvesting tweets representing users within the childhood cancer community</td>
</tr>
<tr>
<td>ACTORS</td>
<td>Parents of children diagnosed with cancer</td>
<td>Composite profiles representing recruited participants</td>
</tr>
<tr>
<td>ACTIVITIES</td>
<td>Tweeting</td>
<td>Close reading and qualitative content analysis of tweets</td>
</tr>
<tr>
<td>OBJECTS</td>
<td>Device used to tweet (i.e. Smartphone, Tablet, Laptop etc)</td>
<td>Suggested for future research</td>
</tr>
<tr>
<td>ACTS</td>
<td>Significant acts described through tweets</td>
<td>Close reading and qualitative content analysis of tweets</td>
</tr>
<tr>
<td>EVENTS</td>
<td>Significant events described through tweets</td>
<td>Close reading and qualitative content analysis of tweets</td>
</tr>
<tr>
<td>TIME</td>
<td>Stage of child’s cancer diagnosis</td>
<td>Close reading of tweets</td>
</tr>
<tr>
<td>GOAL</td>
<td>Themes of conversation as expressed through tweets</td>
<td>Close reading and qualitative content analysis of tweets</td>
</tr>
<tr>
<td>FEELINGS</td>
<td>Benefits and motivations of using Twitter to share child’s cancer experience</td>
<td>Close reading and qualitative content analysis of tweets and email interview transcripts</td>
</tr>
</tbody>
</table>

Table 3 Data synthesis approach – applying Spradley’s 9 dimensions
The analysis conducted with the data harvested for this research study was then aligned to each dimension in order to ensure that the social situation involving parents of children diagnosed with cancer was examined contextually at a sufficient level required for exploring the research questions. Table 3 outlines Spradley’s dimensions, and how they were mapped and interpreted for the purpose of this study. The table also indicates the analysis activities were used to address each of the dimensions in order to understand the phenomenon in a contextual manner.

Spradley’s first dimension for descriptive observation of a social situation is – space. The space in this context was the online community of Twitter users tweeting about childhood cancer. The actors in this scenario were assumed to be the recruited parents of children diagnosed with cancer who own Twitter accounts where stories and perspectives about caring for a child with cancer are expressed. Composite profiles were formed based on the synthesized data to represent the actors as this research study is deeply entrenched in reflecting human interactions through online communication on Twitter (Nilsson et al, 2010; Pruitt & Grudin, 2003; Raybourn et al, 2003). The “activities” of the actors is assumed to be tweeting. Spradley suggests “objects” as a dimension that describes physical objects. In this case, the physical objects were assumed to be the physical devices used for tweeting. The objects however were not considered to be significant for the purpose of answering the specific research questions, and were suggested as an area for future research. The next two dimensions “acts” and “events” were assumed to be the specific individual actions and events described by parents within their tweets. Although Spradley suggests the dimension of time to represent the sequence of events, for the purpose of this study time was assumed to represent the various stages of the child’s diagnosis during which the parent tweeted. The goal was assumed to be the overall themes of conversation emerging from the tweets of parents of children diagnosed with cancer, as these themes represent the thoughts, opinions, and perspectives that the recruited parents intend to express. The last dimension suggested by Spradley is “feelings” which intends to express emotions within the context of the social scenario. This study intends to focus on the expressed motivations for using Twitter to share the child’s story as well as the benefits of using Twitter for this purpose as reported by the recruited participants. Data synthesized following a close reading and detailed qualitative content analysis of the tweets retrieved for this study led to a contextualized understanding of the conversations taking place on Twitter among the recruited parents of children diagnosed with cancer as well as the types of information shared through these tweets.
The “acts” and “events” described by the parents were among the key observations that emerged through the analysis, and the “feelings” expressed in tweets as well as the email interviews were taken into consideration in synthesizing findings of this study. The content coded while analyzing the e-mail interviews was used to situate the context of conversations and shared information within describable patterns. This holistic understanding was then used as the basis of molding composite profiles that closely replicate the phenomenon of parents of children diagnosed with cancer using Twitter as a mode of communication. The themes and codes generated throughout the stages of coding were used to lead into characteristics that differentiated the composite profiles, and the raw data was linked to the final composite profiles through the means of assigning quotes directly from Tweets and e-mail interviews.
Chapter 4
Results

4 Results

The mixed method approach applied using a close reading of tweets from recruited participants as well as obtaining contextual information through e-mail interviews were used to answer the research questions posed for this research study. The results obtained through this method of analysis provided evidence of the phenomenon of using Twitter as an online communication tool by parents of children diagnosed with cancer, and should not be viewed in a generalizable perspective.

4.1 Meet the parents of children diagnosed with cancer

The coded categories following the content analysis of tweets were used as guidelines to form four composite profiles (Solórzano & Yosso, 2002; Eisner, 2005) that represent the tweeting characteristics of the recruited participants while anonymizing their true Twitter identities. The purpose of using composite profiles as a data synthesis approach was to provide an amalgamated representation of the real personalities of the participants of the study, as well as to highlight their overall life circumstances and describe their interaction with social media. A detailed composite profile forming matrix (Appendix E) was used to amalgamate key characteristics of the real participants interviewed in this research study. Each composite profile is described below through a qualitative narrative that provides glimpses of interactions with Twitter as a social media tool used to share the child’s cancer journey are represented in a realistic way that allows individuals within or outside of the childhood cancer community to understand. All names and Twitter user names are fictitious.
Jill’s daughter Tamara was diagnosed with a rare type of childhood cancer 11 months ago. Tamara is currently in treatment and is frequently in and out of the hospital. While Jill maintained a Twitter account well before Tamara got diagnosed, her tweets now focus more and more on Tamara’s experience as well as childhood cancer in general. She does not use any other social media platform. Her Twitter account is used primarily to provide updates about Tamara’s progress with treatment to friends and family. She tweets and retweets occasionally about fundraising initiatives related to childhood cancer, although she isn’t involved in any fundraising initiatives herself. She feels very strongly about issues related to lack of funding and support for childhood cancer research, and frequently tweets about lobbying and prompting the government to allocate sufficient childhood cancer research dollars, as well as for bereavement support for parents who have lost a child to long term illnesses. Jill prefers not to tweet about her personal life. However, sometimes she tweets about how childhood cancer can affect a child’s life as well as the lives of siblings based on her personal experience with Tamara and her two other children. Jill sometimes retweets similar perspectives shared by other parents as well as religious quotes and thoughts shared by others. Jill often posts pictures of Tamara to share the tiny steps towards success in treatment. She does not engage in active conversation much with other parents of children diagnosed with cancer on Twitter, but occasionally retweets posts from other parents. Jill truly feels that tweeting takes up a lot of her time that should be devoted to caring for Tamara, and therefore is thinking about deactivating her Twitter account. While the role of Twitter in her overall support network is circumstantial, it is not one of her major sources of support. Twitter helps her remember that each child’s journey with cancer is different, yet there are countless common threads that run through each of their journeys. She also understands that being in contact with others that can truly relate to what her family is going through can certainly be beneficial for long term wellbeing of her family, however, Twitter is only one of many avenues available to her for support.
Parent Profile B: Jack (Twitter user name @TimsDaddy)

Jack’s son Timothy is currently in remission, however as is common with a lot of childhood cancers, there is a possibility of relapse. Timothy has been home for the past few months and hasn’t needed any hospitalizations in recent months. Jack started Tweeting during his son’s first stay at the hospital following diagnosis. Initially he used Twitter to provide frequent updates from the hospital, and eventually started tweeting about Timothy’s daily life – funny things he said, notable things he did, treatment milestones reached, as well as accomplishments like participating in school plays, etc. Jack also uses Twitter to express thankfulness for Timothy’s life and frequently reminds his followers on Twitter (or anyone reading) to be thankful for every little blessing. Jack passionately tweets about a fundraising initiative that started as a source to fund Timothy’s treatment, and now raises funds for childhood cancer research. He also retweets about fundraising initiatives promoted by other parents of children diagnosed with cancer. Jack is passionate about raising awareness about childhood cancer, and tags (mentions) celebrities and organizations frequently in his tweets to promote childhood cancer awareness. He actively volunteers with organizations involved with childhood cancer advocacy and education, and this experience features frequently in his tweets. Jack never posts images of Timothy. He is very diligent in interacting with other parents on twitter, and actively responds to tweets from other parents. Jack maintains a very detailed blog about Timothy’s cancer experience as well as life in remission, and occasionally tweets links to blog for further details. His tweets cautiously express relief, joy and thankfulness, knowing that cancer can relapse any time. Jack Is a sports enthusiast and frequently shares news articles related to sports events and interesting sports related facts. Jack believes that Twitter helps in reaching people far and wide and he intends to use this platform to use Twitter to share Timothy’s story and raise awareness about the affects of childhood cancer and the need for funding. He feels that the network of parents of children diagnosed with cancer on Twitter is important to him in terms of representing a worldwide network of similar sufferers. Tweeting and raising awareness has certainly helped Jack in accepting the ravaging realities of childhood cancer as experienced by Timothy. Jack and his wife were never able to attend in person support groups held during evenings at the hospital while Timothy was receiving treatment as Timothy’s younger sister was at home. Jack therefore believes that his interaction with similar sufferers on Twitter has helped him immensely, and is a vital part of his support network in terms of coping with his child’s illness.
Parent Profile C: Jane (Twitter user name: @Hope4Lucy)

Jane’s daughter Lucy passed away unexpectedly while in treatment for childhood cancer. Jane had always been very active on Twitter, but Lucy’s diagnosis with cancer and sudden passing had changed her life forever and she essentially had not tweeted during that time. She started tweeting again a few months after Lucy’s death and occasionally tweets about happy memories with Lucy and posts images of the family with Lucy. Jane now runs a charitable fund that provides financial assistance to families coping with childhood cancer, and passionately tweets about fundraising initiatives by her organization. She also frequently re-tweets and promotes fundraising initiatives by other organizations working with childhood cancer causes. Jane frequently posts news clips and videos about childhood cancer awareness and any information about advancements in childhood cancer diagnosis or treatment. Jane prefers not to interact much with other parents of children diagnosed with cancer as she feels that sometimes she gets too attached to the child, which makes her re-live the difficult times her child had faced. She maintains a Facebook page in memory of Lucy also, but does not express much about her personal emotions or difficulty in coping with Lucy’s death on Facebook or Twitter. She is openly antagonistic about religious views in general, but occasionally retweets quotes that could be interpreted from a religious perspective as being positive thoughts and affirmations. She believes in sharing positivity and inspirational quotes that maybe uplifting to other families who have walked the same path as she has with her daughter, and intends to help in supporting hope for other families through her tweets despite not wanting to interact with them directly. Tweeting is not a part of her day to day support network following the death of her child, as she prefers to lean on her friends and family in real life to help her cope with the loss of her child. She feels that tweeting takes up additional time as she primarily maintains her Facebook page, and Twitter is mostly an additional task. She started tweeting in the hopes of reaching a wide group of people with the help of celebrities and public personalities promoting her fundraising efforts in memory of Lucy. Over the past few months Jane has realized that she needs to better coordinate her Facebook page and her tweeting approach in order to get effective results in promoting her fundraising initiative.
Parent Profile D: John (Twitter user name: @LiamsGoldenRibbon)

John’s son Liam was diagnosed with childhood cancer at a stage where there were no further possibilities of cure. Liam passed away three months after being diagnosed. While John already had a Twitter account prior to Liam falling ill, he was not an avid user of Twitter or any other social media platform. During the brief period of time following Liam’s diagnosis, John actively tweeted about Liam’s experience at the hospital and frequent updates about his condition. He used his tweeting experience as a method to cope with the sudden and drastic change in Liam’s health and what followed after. He even tweeted an announcement about Liam’s death. He is fairly religious, and frequently tweets excerpts from religious text in an attempt to make sense of what had happened to his son, and share his thoughts with others. He is deeply engaged in conversation with other parents of children diagnosed with cancer at present, as well as with parents who have lost a child to cancer. Life after the loss of a child, and the devastation caused to a family by losing a child to cancer features heavily in his frequently tweeted topics. It appears that he now uses Twitter as a means to document the process of moving into a future without child and frequently tweets about “letting go.” John is not directly involved in advocacy, but frequently retweets initiatives taken by other parents. John is very diligent in tweeting recently bereaved parents as well as tweeting parents of children going through a rough stage in treatment. He prefers not to share images of Liam, but sometimes retweets images of other children that he follows to share stories of children who are recovering. John started a CaringBridge journal soon after Liam was diagnosed, but did not update it frequently as Liam’s condition deteriorated very suddenly. His interaction with others on twitter isn’t for the purposes of building new relationships, the people he follows on a regular basis are people he knows in real life. John prefers to follow organizations that work with childhood cancer research and is deeply interested in advancements made in childhood cancer care. He feels the need to be involved in childhood cancer advocacy by providing his input wherever possible based on personal experience. John strongly believes that Twitter helps him remain abreast with changes and advancements in the world of childhood cancer, and he feels that this knowledge helps him cope with his circumstances and what happened to his son.
4.2 Themes of conversation

Tweets retrieved methodically from Twitter accounts of participants recruited for this study were also coded and categorized through a detailed qualitative content analysis activity. This analysis identified broad categories of discussion that takes place among the recruited participants on Twitter, and also listed the types of tweets posted and exchanged within each category. At the end of this process, the following list of themes of tweets posted by parents of children diagnosed with cancer who participated in this study was revealed.

i. Social support and coping
   a. Holding on to hope
   b. Sharing personal stories

ii. Casual conversations

iii. Sharing childhood cancer related facts

iv. Providing updates and sharing personal stories

v. Raising awareness about childhood cancer

vi. Providing updates to friends and family

The following sections describe each of the identified themes of tweets posted by parents of children diagnosed with cancer. Each theme is introduced in a table that lists different types of tweets categorized within that theme during analysis. A sample tweet has been included for each of the types discussed. Names and Twitter user names have been masked in the sample tweets to protect privacy of the participants of this study.

4.2.1 Theme: Social support and coping

A mutual phenomenon of social support among the recruited participants appeared to be a dominant theme of tweet. This overarching theme was identified by grouping two themes that appeared to be similar at a granular level. The granular themes were “holding on to hope” and “sharing personal stories.” Detailed analysis of tweets identified that the recruited participants
were tweeting sharing personal stories with each other and mutually helping in providing social support while coping with caring for a child diagnosed with cancer. The following table describes different types of tweets that were found to be aligned with this theme.

### Table 4 Theme: Social support and coping

<table>
<thead>
<tr>
<th>Types of tweets</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Retweeting positive updates from other children</td>
<td>RT @[parent]: [child] started chemo on Monday &amp; is doing well. Keep fighting Little Warrior, we are all behind you. Beat #neuroblastoma</td>
</tr>
<tr>
<td>Asking for prayers for child</td>
<td>Just learnt 1 of [child]’s wee PB friends has relapsed with a soft tissue sarcoma (tumour). Please pray 4 [other child] &amp; his family folks.</td>
</tr>
<tr>
<td>Asking for prayers for someone else’s child</td>
<td>Praying for teen #cancer patient in ICU at UNC fighting for his life, and for his fam. #pray4[child] #fb</td>
</tr>
<tr>
<td>Supportive messages for other parents when child is not doing well</td>
<td>RT @[parent]: Please everyone #prayfor[child] as she goes into the hospice shortly. We need you to #KeepFighting[child] love you so much</td>
</tr>
<tr>
<td>Offering condolences when child passes away</td>
<td>@[parent] so sorry to hear your news.. you are in our thoughts. xx god bless you all xx</td>
</tr>
</tbody>
</table>

The social connection among parents who participated in this study was demonstrated vividly in tweets and retweets that relayed updates from each other’s children. @[parent]: [child] started chemo on Monday & is doing well. Keep fighting Little Warrior, we are all behind you. Beat #neuroblastoma” – said a retweeted post. A parent re-tweeted this message from another parent he follows on Twitter. Re-tweeting and sharing updates about the children of other parents followed on Twitter appeared to be a common practice among the tweets harvested for this study. The updates shared included positive response to treatment, child’s achievements, as well as when the child was not doing too well, or when a child passed away. Support and prayers were offered through kind words and condolences for parents when their child was not doing well, or had passed away. “Searching for meaning as a cancermom... <link to article>” – a parent tweeted about sharing an article written by a Mom she follows on Twitter. This article strongly resonates with her search for solace, and she felt the need to share with her followers to help them cope with their individual circumstances.
“Praying for teen #cancer patient in ICU at UNC fighting for his life, and for his fam. #pray4[child] #fb” – tweeted a parent. The teen fighting for his life was the child of a parent followed on Twitter. “[@[parent] so sorry to hear your news.. you are in our thoughts. xx god bless you all xx” – tweeted another parent to a parent who had recently lost a child to cancer. The brief 140 character limit provides an opportunity to share a succinct message that lets the parent know there are people supporting, beyond the friends and family in person.

“Advice to those new to the cancer world... <link to article>” – tweets a parent. A veteran in the world of parenting children with cancer, this mom shares her insights and experience with parents of newly diagnosed children. A parent on Twitter will likely be immediately drawn to this post.

The overarching theme of providing mutual social support among parents tweeting about their child’s cancer experience was divided into two sub-themes – holding on to hope, and sharing personal stories. These sub-themes are described in the following sections.
4.2.1.1 Holding on to hope

This theme was one of the granular themes that were grouped under an overarching theme – “social support and coping.” The following table provides a list of sample tweets in this theme.

**Table 5 Theme: Holding on to hope**

<table>
<thead>
<tr>
<th>Types of tweets</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sharing quotes about positivity and hope through text and images</td>
<td>Hope is Powerful: We are beginning to remember ?One year ago? details. &lt;link to blog post from one year ago&gt; #pray4[child]</td>
</tr>
<tr>
<td>Sharing inspirational quotes about working together towards a cure</td>
<td>&quot;Alone we can do so little; Together we can do so much.&quot;~H Keller #MakeSomeNoise 4 kids w/ #cancer</td>
</tr>
<tr>
<td>Sharing child's achievements during/after treatment (sitting up, smiling etc)</td>
<td>Day 5 this week at school for [child] tomorrow. He also played at his friends after school today and had a lovely time :-)</td>
</tr>
<tr>
<td>Child's major achievements (sports victories, awards, treatment milestones etc)</td>
<td>A yr ago [child] was recovering from having port put in his chest.2nite playing basketball #pray4[child]</td>
</tr>
</tbody>
</table>

Parents of children diagnosed with cancer, within the individuals recruited to participate in this study, were largely involved in supporting each other’s hopes through encouraging tweets that expressed positivity, support, and inspiration to remain strong and focused throughout a child’s cancer journey.

"Do not pray for an easy life, pray for the strength to endure a difficult one” This quote intrigues me. <link to detailed blog post>” - This tweet was posted by a parent who maintains a blog about his son’s cancer journey. The parent intends to share his perspective on strength and endurance in positively coping with caring for a child with cancer. While the tweet only shares a snippet of his thoughts, he welcomes other parents and interested individuals to engage in conversation by mentioning his own perspective of being “intrigued” by the quote and providing a link to his blog for further discussion.

Another parent shares – “Day 5 this week at school for [child] tomorrow. He also played at his friends after school today and had a lovely time :-)” Being able to attend school throughout the
entire week is an achievement for a child recently lived through treatment for cancer. The parent acknowledges his son’s achievement through his tweet. An expression of happiness, appreciation, and a glimmer of hope. His child is currently in remission.

Some parents are more detailed and elaborate. “This one is about trying to live in the present moment... and parenting! <link to article published in a cancer care magazine>” – tweets a parent. He includes a link to an article published in an online magazine about parenting a child with cancer. This parent reflects on his own family’s ups and downs and intense learning curve in facing his child’s cancer diagnosis. He tweets about his article in order to help other parents remain positive and hopeful through the child’s journey with cancer. His brief but descriptive tweet provides a preview of his perspective – he reminds parents to remain “present” while parenting a child with cancer.

“A story about our vacation away from the cancer world... <link to blogpost with pictures>” – The same parent tweets again. The tweet includes a link to a blog post and online album of pictures from a recent vacation with his son while he was temporarily off treatment. While cancer looms in the backdrop, the tweet focuses on the joy and happy memories with his son diagnosed with cancer as well as his other children far away from a hospital environment. Sharing their happiness and memories with others to inspire and spread positivity despite the inherent presence of cancer.

Reflecting on the early days of a child’s diagnosis, a parent tweets – “May16th,2013: 1 yr ago, today. [child] was airlifted to @[hospital] & not expected to survive. On Sunday we finish a 10K! <link to an image of the family with child at the finish line>.” While the parent emphasizes the child’s achievement of being able to run 10k on Sunday, he also bears witness to the fact that the child was severely ill and not expected to survive just a year ago. Sharing a reason to remain hopeful with other parents starting on the long journey that started for the child a year ago.

A parent who lost her child to cancer tweeted - “Celebrating my son [child name] today on Nat'l Cancer Survivors Day! <link to image of child>.” The parent expresses how he holds on to memories of his son through significant days dedicated to cancer survivors – despite having lost his son to the very same disease. The parent may have lost his son, but by celebrating survivors he remains hopeful for other children walking the same path as his child.
4.2.1.2 Sharing personal stories

This theme is also one of the granular themes grouped under an over arching theme for social support and coping. The following table lists sample tweets.

<table>
<thead>
<tr>
<th>Types of tweets</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sharing story about every day activities</td>
<td>RT @[parent]@[another parent] [child] will be making the big journey to Florida on Monday with her family to undergo Proton Beam Therapy.</td>
</tr>
<tr>
<td>Sharing memories of child after death</td>
<td>Day 1: Finding over 30 videos of [child] that I have never seen. Pics and vids equate to memories now, so I have just gained new memories.</td>
</tr>
</tbody>
</table>

A parent tweets frequently about her personal life following the loss of her son. Recently she found some photos and videos of her son before he got diagnosed with cancer. She shared her thoughts through a tweet – “Day 1: Finding over 30 videos of [child name] that I have never seen. Pics and vids equate to memories now, so I have just gained new memories.” This tweet is prefixed by “Day 1”. This parent went on to tweet 10 more days about how she is dealing with memories of her child.

A follower and friend on Twitter asked a parent about how she is doing as her child had died recently. “@[friend] thank you. I have my moments of being ok...but then days like today happen. This too shall pass. My Moo is watching over me :))” – she tweeted. The tweets examined for this study show that parents of children diagnosed with cancer use Twitter as a platform to provide updates about their child as well as how they are coping.

Some parents also use Twitter to share brief snapshots of everyday life. These activities sometimes include travel plans related to the child’s treatment – “RT @[parent]@[another parent] [child] will be making the big journey to Florida on Monday with her family to undergo Proton Beam Therapy.” Personal stories are also shared about activities unrelated to the child’s cancer experience – family trips to the zoo, random things that the child said or did that day, or even tweets about things that the child has achieved since being off treatment. These tweets represent a glimpse into the personal lives of a family caring for a child with cancer.
4.2.2 Theme: Casual conversations

This theme was identified through a set of tweets that represented casual conversations and exchange of tweets among the recruited participants. The following table provides a list of the different types of tweets that were aligned to this theme, along with sample tweets.

**Table 7 Theme: Casual conversations**

<table>
<thead>
<tr>
<th>Types of tweets</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal interest (sports, events, hobbies etc)</td>
<td><em>So excited! Just found out #NKOTB is touring with 98' and Boyz II Men! @JonathanRKnight please tell me your coming to Canada!!!!!</em></td>
</tr>
<tr>
<td>Sharing news articles</td>
<td><em>Big news for Kids cancer in Switzerland! &lt;link to news article&gt;</em></td>
</tr>
<tr>
<td>Tweeting about regular daily events</td>
<td><em>Happy 12th anniversary to my wonderful hubby!!</em></td>
</tr>
<tr>
<td>Personal opinions</td>
<td><em>Just saw the effects of the Obama tax increase on my (lower) middle class family of five. Thanks.</em></td>
</tr>
<tr>
<td>Responding to other Tweets</td>
<td><em>@[parent] @[another parent] @[another parent] @[another parent] thanks to you all xx</em></td>
</tr>
<tr>
<td>Religious tweets</td>
<td><em>RT @paulocoelho: Lord, bless our week. Let our hearts understand that the fear of suffering is worse than the suffering itself</em></td>
</tr>
</tbody>
</table>

The tweets examined in this study show that parents of children diagnosed with cancer are on a continual quest towards reaching a balance in their daily lives. Apart from tweeting about their experience of caring for a child with cancer or sharing information related to childhood cancer, the participants of this study demonstrated a simultaneous lighter side of life.

“So excited! Just found out #NKOTB is touring with 98' and Boyz II Men! @JonathanRKnight please tell me your coming to Canada!!!!!” - tweeted a parent. Her anticipation and enthusiasm about her favorite bands is expressed loud and clear. Despite childhood cancer encompassing so much of her family life, this parent provides a glimpse of a part of her life that continues alongside her child’s cancer journey as a link to life as she knew it before her child was
diagnosed with cancer. Personal interests, likes and dislikes, as well as individual personalities shine through the shadowy presence of cancer within the thoughts expressed on Twitter.

“Ever had lol funny moments in the midst of tragic ones? @cancer2gether #cancer #funny <link to a blog post by a parent of a child with cancer>” – a parent tweeted on a separate occasion. The link in her tweet leads to a blog post by a parent she follows on Twitter. The post shares some humor and funny experiences within the realm of caring for a child with cancer, and therefore stories that only other parents of children with cancer can relate to. This tweet opens up a thread of tweet exchange and retweets. Numerous other parents join in.

“Just saw the effects of the Obama tax increase on my (lower) middle class family of five. Thanks” – a parent tweets about his personal opinion on current political events, which results in a spur of tweets being exchanged, a miniature political debate involving opinions expressed in 140 characters. Among the participants of this conversation are this parent’s friends and followers on Twitter – including other parents of children diagnosed with cancer. Taking a step out of the childhood cancer world to engage in conversation about the “real” world. Religious beliefs also feature fairly frequently within tweets shared by parents of children diagnosed with cancer – as apparent in the tweets harvested for this study. “RT @paulocoelho: Lord, bless our week. Let our hearts understand that the fear of suffering is worse than the suffering itself” – a retweet from author Paulo Coelho shared by a parent, who frequently shares quotes that are religious or spiritual in nature in an attempt to make sense of the loss of his son, as well as to share his thoughts with fellow bereaved parents.

The Twitter universe by nature of micro-blogging is a breeding ground for quick chats and exchanges of mass messages. Parents often find themselves exchanging quick pleasantries with other parents of children diagnosed with cancer, as a note of assurance of support and friendship. While some parents choose not to interact much with other parents of children diagnosed with cancer as she finds it very difficult, other parents prefer to follow more and more parents of children diagnosed with cancer as a part of their support network. A common phenomenon observed within the community of parents of children diagnosed with cancer is acknowledging new followers - “@[parent] @[another parent] @[another parent] @[another parent] thanks.” – tweets a parent as each of these users sent him requests to follow. Perhaps this brief
acknowledgement could grow into an important source of friendship and support from someone going through the same experience. Apart from acknowledgements, some parents maintain constant interaction with followers on Twitter by responding to tweets posted by other parents of children diagnosed with cancer on a regular basis by answering questions or simple exchanges of daily conversation. Some parents are quite meticulous about keeping track of new followers as well as his interactions on Twitter. A parent recruited for this study uses a Twitter add-on to track his weekly activity – “My week on twitter: 14 retweets received, 19 new followers, 72 mentions. Via: <link to website>.”

Despite the chaos, anxiety, and uncertainty brought about by childhood cancer that can have drastic affects on a family, parents of children diagnosed with cancer have found to maintain an attempt at some sense of normalcy in daily life by sharing bits and pieces of their pre-cancer lives – “Happy 12th anniversary to my wonderful hubby!!” – tweets a parent, despite her daughter being in and out of the hospital for ongoing chemo therapy. Her child’s hospitalizations and treatment procedures have been internalized as a part of their regular family life, as apparent in this parent’s tweet wishing her husband a “happy” anniversary. This tweet appeared among a slew of other tweets related to her child’s cancer experience, but the parent is able to compartmentalize childhood cancer from the happy occasion of her anniversary through a tweet completely unrelated to childhood cancer.

### 4.2.3 Theme: Sharing childhood cancer related facts

This theme emerged from tweets that were related to sharing factual information related to childhood cancer. The following table provides examples.
Table 8 Theme: Sharing childhood cancer related facts

<table>
<thead>
<tr>
<th>Types of tweets</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tweeting about clinical trials - used by own child or provided by certain hospitals/health care providers</td>
<td>RT @TNCI: We move completed promising research into clinical trials. We are one of the few organizations working in this area. &lt;link to website&gt;</td>
</tr>
<tr>
<td>Answering questions from followers/other parents related to child's cancer experience</td>
<td>@[parent] I haven't heard of it. [child]’s treatment is also a trial based on her receiving my immune system/t-cells in place of hers.</td>
</tr>
<tr>
<td>Sharing links about childhood cancer related fundraising events and opportunities</td>
<td>RT @[parent]: Need financial/practical help in the UK? Visit &lt;link to website&gt; #BrainTumorThursday</td>
</tr>
<tr>
<td>Suggestions for improvement in cancer care</td>
<td>Every Child going through chemotherapy should have a chemo buddy to help him or her play away the fear. Please... <a href="http://t.co/N5IvdBVmG">http://t.co/N5IvdBVmG</a></td>
</tr>
</tbody>
</table>

The childhood cancer community on Twitter, as represented by the parents of children diagnosed with cancer recruited for this study, appeared to be pro-active in sharing any information that was deemed relevant in caring for a child with cancer. A parent tweeted about the long term side effects of childhood cancer as experienced by her child – “The issue of cancer treatment side effects, especially long term ones... #sideeffects #cancer <link to article>”. Another parent shared information about how to deal with hair loss through her blog, and shared the link through a tweet – “New post about #childrenscancer and the "hair issue"  <link to article>.”

While these tweets include links to articles and blog posts published by the author him/herself, some parents choose to share informative news articles and online posts “Big news for Kids cancer in Switzerland! <link to news article>.” Information about clinical trials and innovative or alternative treatment options are also shared through tweets and re-tweets – RT @TNCI: We move completed promising research into clinical trials. We are one of the few organizations working in this area. <link to website>. Some parents go the extra distance and share their personal experience with clinical trials in order to provide additional information that may arise in the minds of a parent trying to decide about clinical trials for their own child. A parent responds to questions asked by another parent about clinical trials - @[parent] I haven’t heard of
it. [child]'s treatment is also a trial based on her receiving my immune system/t-cells in place of hers.

Helpful information like contact information for financial advisors specializing in helping families with ill children is retweeted by a parent - RT @[parent]: Need financial/practical help in the UK? Visit <link to website> #BrainTumorThursday

4.2.4 Theme: promoting campaigns and fundraising

This theme emerged from tweets that were sharing information about recent campaigns and fundraising initiatives. The following table provides examples.

<table>
<thead>
<tr>
<th>Types of tweets</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Posting links to fundraising page for own child</td>
<td>@Radio_Exe Please RT our fundraising event raising money for [child]'s appeal. A mention on air would be great too? &lt;link to fundraising page&gt;</td>
</tr>
<tr>
<td>Posting/retweeting links to fundraising page</td>
<td>RT @teamlewis06: For every follower we kindly have £1 donated to our fundraising. Help us to raise awareness about Krabbe Leukodystrophy</td>
</tr>
<tr>
<td>for other child or organization raising funds for childhood cancer</td>
<td></td>
</tr>
<tr>
<td>Tweeting about personal involvement in fundraising initiatives</td>
<td>Mum's just gearing up 4 her 12 mile run. If u see her out &amp; about on the streets of Gosport, don't forget 2 toot! Txt JOB090 £? to 70070.</td>
</tr>
<tr>
<td>Promoting fundraising events - fundraising run/walks, hair donation, lemonade stand etc.</td>
<td>RT @AlexsLemonade: The weekend is here and many families and groups are hosting Alex’s Lemonade Stands! Find one near you:  <a href="http://t.co/d78">http://t.co/d78</a>?</td>
</tr>
</tbody>
</table>

One of the most common and popularly shared themes appearing in the tweets analyzed for this research study was raising funds for childhood cancer related causes. Whether it was a parent of a child recently diagnosed with cancer, a parent caring for a child currently in treatment, a parent of a child in remission, or a parent of a child who had passed away from cancer – all appeared to be equally involved in sharing and promoting fundraising initiatives across geographic borders. The purpose of raising funds and how the funds were going to be used however differed
significantly depending on the location of the child. The geographic location of the child wasn’t always specifically mentioned in the self-identification information for the Twitter accounts, but in all cases a general inference could be made based on the tweets being analyzed. Families living in the US very frequently were involved in raising funds for their own child’s treatment related expenses as health care expenses were a commonly tweeted about issue. A parent living in the UK was raising funds to travel to the US where a clinical trial could potentially save the child’s life. In general however, fundraising initiatives for childhood cancer research and financial support for families with children with cancer was a focus across the board.

The styles of promoting fundraising initiatives through tweets however differed widely. “RT @teamlewis06: For every follower we kindly have £1 donated to our fundraising. Help us to raise awareness about Krabbe Leukodystrophy” - tweeted a parent who was actively increasing the number of followers on Twitter and therefore did not need a focused audience. This parent’s approach was to tweet as many people as possible in order to increase the number of followers so that the amount of funds donated increases accordingly. A direct interaction was not required with the followers.

Another parent of a child currently in remission, had a more focused approach in communication. “@Radio_Exe Please RT our fundraising event raising money for [child]’s appeal. A mention on air would be great too? <link to fundraising page>.” The parent intended to reach a select few influential Twitter users who could assist in reaching potential donors to support her fundraising initiative. In this particular tweet, the parent is reaching out to a local radio station requesting coverage for his son’s story.

A parent shared updates from a recent fundraising initiative she was involved in – “The Calendar of Hope raised over 16,000 for kids with cancer! <link to fundraising website>.” This brief update provided information to her followers and friends who had participated in the fundraiser she participated in by demonstrating success directly instead of having to follow up with each donor individually.
4.2.5 Theme: Raising awareness about childhood cancer

This theme emerged from tweets that were posted by parents in raising awareness about childhood cancer based on their personal experience as well as by sharing tweets posted by others. The following table provides examples.

Table 10 Theme: Raising awareness about childhood cancer

<table>
<thead>
<tr>
<th>Types of tweets</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sharing own child's story through text and images</td>
<td>[child] had a platelett transfusion this evening. Nurses were so proud to see her so well. Weight now 14.85kg &lt;link to image&gt;</td>
</tr>
<tr>
<td>Tweeting/retweeting about another child's story</td>
<td>RT@[parent]: [child]'s not very well today, getting weaker by the day but she is fighting as hard as she can. Please #prayfor[child] &lt;link to image&gt;</td>
</tr>
<tr>
<td>Tweeting/retweeting about organizations focused on childhood cancer initiatives</td>
<td>@connect4cancer thank you. We walk this path with so many, yet it is a long lonely journey. Your support means a lot.</td>
</tr>
<tr>
<td>Sharing news links and articles about childhood cancer</td>
<td>RT @CancerCureNow: CancerCure: Pediatric Cancer - Guest Article &lt;link to article&gt;</td>
</tr>
<tr>
<td>Reaching out to celebrities to raise awareness through retweets and follows</td>
<td>@britneyspears hi, please follow my daughter [child] shes 3 and has neuroblastoma cancer..we want to raise awareness of this illness</td>
</tr>
<tr>
<td>Using cancer related hashtags to promote topic on Twitter</td>
<td>#ChildhoodCancer Effects the WHOLE FAMILY. [child] and his big sister, [sister's name]. &lt;image of child and sibling&gt;</td>
</tr>
</tbody>
</table>

Raising awareness about childhood cancer is one of the key themes of tweets posted by the recruited parents of children diagnosed with cancer on Twitter. Although aiming for a common goal of raising global awareness about childhood cancer, the parents participating in this study had very different styles of expression. A parent tweeted vivid descriptions of her child’s experience in order to raise awareness about the harrowing affects of childhood cancer. She posted a picture, for example, of her daughter before being diagnosed with cancer, as well as an image of her during treatment in the hospital to show the stark changes in her daughter’s physical appearance. “This was my baby. This is what #ChildhoodCancer does to an innocent child. Be
Aware. “– she tweeted. While not all parents are willing to share pictures of their ill child, this parent chose to share before-and-after images of her daughter within a tweet using a hash tag to draw attention to the topic of childhood cancer. Not all parents, however, choose to share such intimate photos of their child’s cancer experience.

Some parents tweet about organizations that work directly or indirectly with childhood cancer related causes, and raise awareness about the types of support services available for families caring for a child with cancer, or about new and innovative advancements in childhood cancer diagnosis and treatment. A common practice observed within the tweets analyzed for this study was reaching out to celebrities through tweets requesting them to share their child’s story to gain a larger audience for awareness.

Hash tags are a way of drawing attention within Twitter, and the overall subject area of childhood cancer has its own share of popularly used and defined hash tags. “#ChildhoodCancer Effects the WHOLE FAMILY. [child] and his big sister, [sister’s name]. <image of child and sibling>” – tweeted a parent. While hash tags did not appear to be used consistently or in a well defined structured manner, the role of hash tags in drawing attention towards childhood cancer related causes was acknowledged by some of the parents recruited for this study. There did not appear to be any existing constructive or coordinated initiative in using childhood cancer related hash tags in a beneficial way to organize knowledge within the childhood cancer community on Twitter. Some of the common hash tags used within the tweets analyzed for this study included #childhoodcancerawareness, #babycancer, #childcancer as well as hash tags mentioning names of specific types of childhood cancer.
4.2.6  Theme: Providing updates to friends and family

This theme emerged from tweets that were posted by parents providing updates about their own child’s cancer treatment or sharing updates about other children. The following table provides examples.

Table 11 Theme: Providing updates to friends and family

<table>
<thead>
<tr>
<th>Types of tweets</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tweeting updates about child’s treatment</td>
<td>[child] yesterday got moved to intensive care due to fluid on her lungs, not been able to breathe. She is on a ventilator and on many meds</td>
</tr>
<tr>
<td>Re-Tweeting updates from other children</td>
<td>RT [@parent] @[another parent] [child] will be making the big journey to Florida on Monday with her family to undergo Proton Beam Therapy.</td>
</tr>
</tbody>
</table>

Some of the parents who participated in this research study noted the usefulness of Twitter in providing updates to friends and family about their child’s progress through treatment, or providing updates during long hospital stays and critical moments in treatment. Parents have gone to the length of sharing the death of their child through tweets -

“6.10am 14.8.12 [childname] died surr. by love at home. THKYOU @mariecurieuk @CLIC_Sargent. B Brain Tumour Aware @HeadSmartUK Over & Out #cancerchild” – said one parent, thanking organizations that had supported the family during the child’s cancer journey as well as promoting an organization that raises awareness and funds for children with brain tumours similar to her child. The fact that this tweet was posted minutes after the child had died affirms the role of Twitter within the parent’s overall experience with her child’s illness. A close reading of the tweets harvested for this study revealed that this parent had been actively tweeting about her child’s long journey with cancer, and had frequently tweeted about personal and intimate details of the child’s treatment, side effects like hair loss, dementia, and vivid details of how his condition deteriorated over the months following diagnosis. She had gained an avid group of followers apart from friends and family in real life who got attached to the story she shared through glimpses of her son’s journey through her tweets, and therefore she may have felt the need to share the news of her son’s passing with the seemingly close knit network of
followers. It may have also been a way for herself to fully comprehend that her son had in fact passed away after his long battle – and publishing a tweet for the world to know may have been a means for herself to accept what had happened minutes after her son’s passing. Similarly, another parent tweeted a few hours after her child’s passing - “Heaven gained a beautiful Angel, this morning. My baby has gained his wings. #ChildhoodCancer.”

The depth and range of updates shared on a public platform like Twitter depends on the perspective of the parent tweeting. However, the powerful statement of a parent tweeting about the death of a child moments after the child has died demonstrates the intense engagement and dependency that occurs on Twitter within the childhood cancer community.

Other parents choose to provide updates about routine treatment related events – “Chemo number 22, check. Only 4 more to go.” A brief update, but enough information to keep friends and family abreast of the child’s treatment procedures. “[childname] had a platelett transfusion this evening. Nurses were so proud to see her so well. Weight now 14.85kg x <link to image of child>” – a parent tweeted specific updates about her daughter.

“A day on the chemo ward, part 1... <link to detailed story>” – tweeted a parent, while his son was in a hospital receiving chemo. A link is provided to a detailed note on Facebook with pictures of the child during the process of receiving intravenous chemo drugs, his surroundings, the view from his window. This post is followed by 3 more notes – part2, part3, and one final part. Each note elaborating the happenings of a day in the life of a child in a chemo ward.

4.2.7 Organizing themes within everyday life information seeking framework

Concepts of everyday life information practice described by Savolainen (1995) were applied to organize these themes. The framework of everyday life information seeking introduced by Savolainen (1995) conveys a relationship between the “way of life” and “mastery of life” through the social context within which people engage in problem solving behavior when encountered by critical incidents. Way of life and mastery of life are influenced by values, conceptions, as well as the current phase of life. Savolainen describes the way of life to be the series of choices people have to make in everyday life. When faced with incidents that occur in everyday life that require pragmatic problem solving, one’s mastery of life indicates the ability to
“approach everyday problems in certain ways in accordance with one’s values” (Savolainen, 1995). In the context of this study, dealing with life circumstances following a child’s diagnosis with cancer can be viewed as an incident that requires pragmatic problem solving in terms of dealing with the new circumstances of everyday way of life. While the concepts introduced by Savolainen are primarily focused on the activity of information seeking, the framework of relating way of life and mastery of life through social context can be applied to information use and sharing as well. Savolainen (2007) posits that information sharing is an activity involving giving and receiving information within the same context. Twitter as a tool used by parents of children diagnosed with cancer provides an environment for information seeking as well as giving and receiving. Savolainen’s empirical analysis based on interviews with 20 environmental activists in Finland in 2005 led to describing the motives for sharing information in everyday life situations. These motives, described below, provide a structural approach to describe the activity of sharing information within the context of everyday life circumstances.

i. Serendipitous altruism to provide help to others – sharing information out of kindness or goodness of heart.

ii. Pursuit of the ends of seeking information by proxy – receiving information sought by others.

iii. Duty-driven needs characteristic of persons elected to positions of trust.

The following is a description of the information sharing motives introduced by Savolainen (2007), and an explanation of the key themes of tweets posted by parents of children diagnosed with cancer in this study. The themes are described in relation to a motive with which they closely align.

---

**Serendipitous altruism to provide help to others – sharing information out of kindness or goodness of heart.** This motive was aligned with the theme of mutual social support within the childhood cancer community on Twitter, and was characterized by supporting others in similar circumstances by helping them hold on to hope, as well as by tweeting about personal stories of caring for a child with cancer. Casual conversation was another key theme identified which aligned with the motive to altruistically share information with other users on Twitter.
Key themes identified-
1. Social support
   i. Holding on to hope
   ii. Sharing personal stories
2. Casual conversations

**Pursuit of the ends of seeking information by proxy – receiving information sought by others.**

This motive is characterized by seeking or coming across information that maybe relevant or important to others, and subsequently sharing that information. The two key themes identified which aligned with this motive were sharing childhood cancer related facts, as well as promoting campaigns and fundraisers.

Key themes identified -
1. Sharing childhood cancer related facts
2. Promoting campaigns and fundraisers for childhood cancer related causes

**Duty-driven needs characteristic of persons elected to positions of trust.** In the context of tweeting about a child’s experience with cancer, a parent who has taken care of a child with cancer creates a certain extent of credibility and trust for the themes identified - raising awareness about childhood cancer and providing updates about a child’s progress with treatment or current activities.

Key themes identified –
1. Raising awareness about childhood cancer
2. Providing updates to friends and family

Posting tweets inherently represents a context of information sharing where the individual tweeting gives information to either a specific receiver or an unspecified group of readers. The themes of tweets identified through qualitative content analysis were organized based on the 3 motives for sharing information as identified by Savolainen (2007). While some of the themes
could be aligned with more than one of Savolainen’s motives, the closest match in the context of the underlying tweets was chosen for each theme.

The following is a summary of the key themes identified through qualitative content analysis of the tweets organized according to Savolainen’s (2007) three motives:

Table 12 Summary of key themes of tweets (arranged by motives for information sharing)

<table>
<thead>
<tr>
<th>Serendipitous altruism</th>
<th>Sharing information sought by others</th>
<th>Duty-driven sharing</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Social support and coping</strong></td>
<td><strong>Childhood cancer related facts</strong></td>
<td><strong>Raising awareness about childhood cancer</strong></td>
</tr>
<tr>
<td>- Holding on to hope</td>
<td>- Sharing personal stories</td>
<td>- Providing updates</td>
</tr>
<tr>
<td><strong>Casual conversations</strong></td>
<td><strong>Promoting campaigns and fundraisers</strong></td>
<td><strong>Providing updates</strong></td>
</tr>
</tbody>
</table>

4.3 Tapping into perspectives of a parent

The responses received through e-mail interviews were analyzed to identify the reported benefits and motivations for using Twitter to share thoughts and perspectives about a child’s cancer experience. Not all respondents described their experience with Twitter as being beneficial. Some respondents mentioned reasons that led to a decision to stop using Twitter as a tool to share their child’s cancer experience.

Similar to the analysis of themes that emerged from the Tweet content, analysis of the e-mail interviews was also organized based on the motives of information sharing (Savolainen, 2007). The motivations reported by the participants for choosing Twitter are described below within the context of the three motives of information sharing. An additional motive (receiving support and information) has been suggested as an extension to Savolainen’s framework based on the findings of this research study.

**Altruism – supporting others**

Savolainen (2007) suggests that people are prone to sharing information with others out of a sense of goodness or kindness. Some parents mentioned that the ability to connect and share information with other parents of children diagnosed with cancer provided a sense of being in a
community that understands what it means to care for a severely ill child. Some of the parents interviewed revealed the role that their interaction with other users on Twitter played in coping with their child’s illness experience. The motivation to share information with other parents to provide an environment of mutual support therefore suggests altruistic intentions.

“While the story for each child is always unique, there are countless common threads that run through each of their journeys. Being in contact with others that can truly relate to what you have gone through can only be of benefit in the long run.”

While the act of tweeting is not a typical tool expected to help with the process of coping, a parent mentioned that raising awareness about the realities of childhood cancer by sharing personal experiences helped with the process of understanding and accepting “what happened/is happening” to the family. This parent also mentioned that it was very difficult to attend the in person support groups hosted by the hospital as they were held in the evenings. The hospital was an hour’s drive away from home, and they had two more children along with the child diagnosed with cancer, which made it difficult to dedicate additional time to support groups. This parent alluded to the traumatic affects that childhood cancer can have on a family, suicidal siblings for example – and mentioned that social media is “massively important” in helping the parents facing an imminent breakdown in the family to remain connected with social support and people who understand.

A parent also mentioned that sometimes women are more likely to connect with other mothers of children diagnosed with cancer while their child is in a hospital or a clinical setting through simple conversation; however men tend to have a more difficult time connecting in person. Social media in these circumstances can play an important role in providing fathers with an opportunity to seek and find support in a seemingly anonymous environment that maybe perceived as safe and secure to share feelings within.

Some parents mentioned that tweeting is an important part of a “worldwide network of similar sufferers”, but is viewed separately from the day to day support from “friends, family, community, and the doctors.” The different approach to seeking support through tweeting was rather apparent in meeting other people going through similar life experiences, and being able to share advice sharing, and thoughts.
“I’m aware that my tweets had a very particular, short, specific use,” said one respondent – “which is probably not what other users are doing. They were only for those few weeks he was dying but they were in a way the most important weeks of all as they summed up our family & community and how our sick child fitted into it and how we represented a national campaign. Many, many people have told me how affected they were by them & I’m so glad I overcame my social media terror & did it.” Powerful statements like these summarize how tweeting has played a significant role in empowering families going through the unimaginably difficult times while losing a child to cancer. This respondent highlights the role played by twitter in providing the ability to share their story in order to highlight a national campaign related to raising awareness for childhood cancer.

A major role played by Twitter in the journey of childhood cancer as experienced by a parent is to spread and share positive thoughts to support the hope of a happy ending. A respondent highlighted the idea of feeling supported by other families going through a similar experience, sharing advice, stories, and positivity can always be helpful. When asked what the preferred topics to follow on twitter were, one respondent mentioned – “anything that can raise awareness, but more importantly anything that can put a positive spin on what we have all been going through.”

The participants recruited for this study appeared to post tweets that include links to websites and videos that share information about new research and advancements that maybe beneficial to families seeking that kind of information – providing a reason to be hopeful.

*Sharing information sought by others*

Savolainen (2007) posits that sometimes people tend to seek and share information that they know will be valuable to others. Twitter is widely used to share information about non-profit organizations created in honor of a child lost to cancer, or a fundraising campaign to support treatment for a child, or simply to promote initiatives related to childhood cancer awareness, and advocacy. These tweets can inform individuals seeking information about how to contribute towards childhood cancer related causes. The ability to reach a wide audience including celebrities and politically influential individuals and organizations through a brief tweet, or
through sharing a link or video encouraged some parents of children diagnosed with cancer to choose Twitter as a platform to promote fundraising initiatives and advocacy campaigns.

“It is helpful to be in contact with people/organizations that are engaged in the fight against childhood cancer from many different approaches. Awareness comes from both sharing my stories as well as listening to those of others.” – said one respondent. Yet another respondent who viewed this statement from a different perspective in saying that it is convenient to use Twitter to “keep an eye” on what is going on in the world of childhood cancer, however devoting too much time by following other families on Twitter can take away from much needed attention for the ill child. “I’m disciplined about it, because I need to be.” – concluded this respondent by highlighting the need to effectively prioritize responsibilities while caring for a child with cancer.

**Duty driven motivations**

The ability to reach an audience far and wide, beyond immediate family and loved ones, provided a quick and effective way to raise global awareness on Twitter about the realities of childhood cancer. Some parents reported being chosen to be ambassadors for childhood cancer awareness within their community, or by organizations working with childhood cancer. These parents discussed using their Twitter feeds to share stories about their child’s experience in order to raise awareness. These circumstances are directly aligned with Savolainen’s (2007) suggestion that in some situations individuals feel the need to share information as their placed in a position of authority. In reference to sharing personal experience of caring for a child coping with extreme side effects of cancer treatment, an interview respondent said -

“*Child death, dementia, care in the community, cancer are huge subjects that people find very difficult but they told me afterwards that these tiny glimpses were incredibly powerful.*”

This parent mentioned that as the number of followers on his Twitter account increased, he was approached more and more both in person as well as online seeking to discuss and asking about childhood cancer, specifically about his child’s experience. This parent had always been candid and upfront about describing the side effects experienced by his child, he felt that people outside of the childhood cancer community were not usually aware about the realities of caring for a child with cancer, nor were they familiar with comprehensible information about childhood cancer. The respondent felt that he would be able to contribute towards providing people outside
of the childhood cancer community with a glimpse of his family’s reality and raise awareness about the effects of childhood cancer as well as the enormous need to research in this area of oncology. Mentioning the ability to reach a wide audience through Twitter, one parent said -

“Twitter has more of a reach and is more inter-connected than Facebook. Using Retweets and Hashtags, it is easier to draw more people with similar goals and issues to the account.”

Parents reported tweeting celebrities, government officials, politicians, and influential organizations to retweet their child’s story in order to reach a larger audience for the purpose of raising awareness about childhood cancer. Parents also expressed the usefulness of Twitter in seeking information about research studies and advancements in childhood cancer care by links, videos, and information shared through tweets.

An additional motive – receiving support and information

Savolainen (2007) describes the motives for sharing information primarily based on a framework of information seeking in the context of everyday life. The motivations for sharing information related to a child’s cancer experience through Twitter were aligned with Savolainen’s motives within the context of information seeking needs of individuals reading the tweets rather than the needs and perspectives of the individual posting tweets. The motivations Savolainen describes as altruistic, providing information sought by others, as well as duty driven motivations are all in some way aligned towards meeting information needs of others. Some parents however described their motivations for tweeting in order to connect with a “world-wide network of similar sufferers” on Twitter. In referring to similar motivations, one parent said – “Being in contact with others that can truly relate to what you have gone through can only be of benefit in the long run.” While these parents described altruistic intentions for contributing information and support through tweets that help foster a community of individuals tweeting about their child’s cancer experience, they also expressed their motivation for tweeting to be a part of this community in order to receive support and information themselves. Viewing the act of posting tweets to share information about a child’s cancer experience from the perspective of the parent choosing to meet their own needs is not currently described within Savolainen’s framework. Findings from this research study therefore suggest that the framework for everyday life information seeking, specifically within the area of problem solving when faced with critical
incidents, can be extended to include circumstances where information is shared not only to meet the needs of others, but also to meet the needs of oneself.

4.3.1 Reported benefits

Twitter was identified to be a relatively convenient tool identified by the respondents. A parent who maintains a website dedicated to the child’s cancer journey expressed the convenience of using a Twitter widget on the website to provide quick and effective updates about the child to friends and family. The Twitter widget populates current information and updates on the family’s activities as posted on Twitter directly to the website without having to go through the complicated steps of updating the website directly by logging into the account for changes several times a day or week. This parent also expressed that the ability to tweet conveniently from a smart-phone or tablet PC was advantageous while caring for a child with cancer.

Some parents mentioned that convenience of micro-blogging as a reason for choosing Twitter to share the child’s cancer journey – “I chose Twitter exactly because it’s so short!” This parent highlighted the convenience in terms of posting a short message that can reach a wide number of people, as well as the convenience of the people waiting for an update from the parents being able to read a short and quick update rather than having to read details in a blog for example.

The convenience of being able to upload photos of the child, and share links to blog updates as well as quick updates of significant changes in the child’s circumstances were also tweeted conveniently.

4.3.2 Reported experiences that were not perceived as beneficial

Not all experiences with Twitter in terms of sharing a child’s cancer experience were reported as beneficial and convenient. One respondent expressed that while tweeting does play a role in their family’s overall support network, it does not feature to a great degree. One parent responded by saying that his wife does not like discuss their experience as a family caring for a child with cancer publicly, but the Dad continues to share bits and pieces of their story. A respondent identified that sometimes tweeting can get too time consuming and distract from regular daily activities that are much needed in caring for an ill child. “I haven’t built any relationships over Twitter.” – mentioned one respondent – “Several parents I follow, I already knew.”
“I am considering closing my account as when I tweet and get many replies, I feel obligated to reply when [child] should be my priority”

A respondent raised the controversial topic of difference in opinion with other parents caring for children diagnosed with cancer, or simply other people on Twitter being judged about life choices. This topic was raised in reference to “other parents who become over-bearing and preachy about what needs/should have been done.” – said the respondent. “We all did/are doing what we think is best for our child, and someone claiming higher moral ground based on religious beliefs, and or financial and educational standings doesn’t really help anyone.” The ability to reach users far and wide through Twitter, while extremely helpful in some circumstances, can invariably become the cause of conflict and tension for parents of children diagnosed with cancer when such situations arise.
Chapter 5
Discussion

5 Discussion

The purpose of this research study was to identify the key themes of tweets posted by parents of children diagnosed with cancer, as well as to investigate the motivations reported by the parents for using Twitter as a social media platform to share personal insights related to the child’s cancer experience. The objective was to place the research findings within the context of online health communication that reflects personal accounts of illness experience. Detailed coding, categorization and overall exploration of tweets and e-mail interview transcripts was conducted iteratively until subjective interpretation of the data was succinct and saturated when no more new codes emerged from analysis.

The categories that were identified through coding tweets and e-mail interview transcripts were synthesized into 4 composite characters that represented tweeting characteristics of a hypothesized group of Twitter users who are parents of children diagnosed with cancer. The composite profiles collectively represented the 15 parents recruited for this study. The purpose of creating these composite characters was to provide familiarity with the tweeting characteristics of the recruited participants without using identifiable information. The composite characters provide context and background for the research questions answered in this study by indicating tweeting style and preferences, priorities and perspectives.

5.1 Research findings

5.1.1 Research question 1: Key themes of conversation

A close reading and content analysis of tweets collected from accounts of parents recruited for this research study revealed underlying themes of topics posted on Twitter by parents of children diagnosed with cancer. While the key themes identified by this study may not be an exhaustive list of all themes discussed within the childhood cancer community, and only represents the tweets harvested for the purposes of this study, the word cloud generated from a wider set of tweets collected by an open-ended text based search for “childhood cancer” provides a relative comparison of the community as a whole with the topics revealed by content analysis.
The key themes that emerged from the content analysis categories included raising awareness about childhood cancer, holding on to hope, social support and coping, promoting campaigns and fundraising, sharing relevant childhood cancer related information, providing updates and sharing personal stories, and casual tweets about topics of interest unrelated to the child’s cancer experience.

In a study involving narrative analysis of blogs published by parents of children diagnosed with cancer, Heilferty (2009) suggested further research on other modes of online communication used by parents of severely ill children – including the use of Twitter. Heilferty weaved complete stories of illness applying life story analysis techniques by stringing together bits and pieces of the stories as posted in individual blog posts. The purpose of Heilferty’s study was to situate research findings within a broader context of studies leading to the potential development of a theory of online communication during illness. Heilferty revealed underlying meaning from blog posts from the perspective of the author, the reader, as well as health care professionals. The key themes that emerged from analysis of tweets posted by parents of children diagnosed with cancer revealed in this study could be viewed in a similar three-tier manner. The themes identified in this study could be interpreted in different ways when viewed from the perspective of the parents who tweet about their child’s cancer experience, from the perspective of readers who follow tweets of parents with children diagnosed with cancer, as well as from the perspective of health care and support professionals who work with families caring for children diagnosed with cancer. Each of these perspectives, Heilferty suggests, can add value to existing research on developing a theory of online communication during illness.

The tweets examined for the purposes of this study provided occasional glimpses of a story of a family travelling along on the child’s cancer journey. Compared to Heilferty’s analysis of continuous stories published on blogs, however, Twitter allowed larger discontinuities in the storyline and some room for imagination created by the limitation on the amount of text that can be expressed within a single tweet. The key themes of tweets revealed in this study reveals that the parents are not using Twitter to chronicle their child’s story of living with cancer, rather expressing intermittent opinions, feelings, thoughts and perspectives that arise from their child’s experience. The topics posted on Twitter therefore constitute of a “fractured” storyline told by “simultaneous narrators” – describes King (2013) in a blog post about how Twitter is reshaping
the future of storytelling. The 140 character limit imposed by the Twitter platform did not appear to limit the content shared by parents of children diagnosed with cancer. Parents shared links to detailed blog posts, Facebook pages, articles, images, and other websites to express verbose thoughts and perspectives. Fear, anxiety, exhaustion and other emotions brought on by the uncertainty of a child being diagnosed with cancer or having lost a child to cancer were present but not always explicit in tweets posted by the participants. Frequent tweeting about childhood cancer advocacy based on factual information for example was often accompanied by feelings and opinions of frustration over the lack of funding for childhood cancer research or social and financial support. Tweets related to raising awareness about childhood cancer using statistics available on public websites sometimes highlighted the difficulties faced due to a delayed diagnosis, or having to travel a long distance for treatment facilities – scenarios described from personal experience. Results of extreme side effects and the physical effects of specific types of treatment were sometimes expressed through updates provided to friends and families. Parents exchanging tweets in a conversational manner often revealed details about their own child’s cancer experience that may not otherwise be known to people outside of the community.

Despite the imminent uncertainty of caring for a child with cancer or the complex emotions of losing a child, the remarkable presence of hope and positivity in facing such challenging circumstances illuminated the fragmented stories, experiences and opinions expressed by the participants of this study. While not all participants knew or followed each other on Twitter, upholding hope and mutual support during difficult times through positive and supportive tweets directed at parents of children experiencing a particularly rough period appeared to be a common phenomenon. The underlying representation of a virtual community of individuals who understood each other’s experience truly stood out throughout the analysis of the key themes of conversation among parents of children diagnosed with cancer.

While all the parents recruited for the purpose of this study self identified on their Twitter profile as a parent of a child diagnosed with cancer, the extent to which childhood cancer featured within their tweets varied widely. Some parents intertwined topics of personal interest along with their child’s experience with cancer, while some parents chose to tweet only about childhood cancer advocacy and awareness. Two of the parents participating in this study maintained a personal Twitter account, as well as a separate Twitter account dedicated completely to the
child’s cancer experience. Reported motivations and perceived benefits of using Twitter, as analyzed in the second research question, alludes to some insight about what drives the parent’s level of engagement with Twitter.

5.1.2 Research question 2: Reported benefits and motivations for using Twitter

The responses received from e-mail interviews were analyzed to identify the reported motivations for using Twitter, as well as the perceived benefits. The responses received were organized by the key themes identified in response to the first research question to clearly describe reported benefits and motivations for using Twitter as a platform to share insight and information related to a child’s cancer experience. As expected however, not all recruited participants reported their experience with Twitter to be beneficial in the context of their child’s cancer journey. In fact, some parents reported experiences that led them to consider deactivating their Twitter accounts. The motivations for choosing to tweet about their child’s cancer journey varied significantly among the participants interviewed, and motivations also appeared to change over time for some participants.

The motivations for using Twitter as a tool to engage in childhood cancer discourse appeared to differ depending on the stage of diagnosis of the child. While the key themes identified through detailed analysis provided insight into priorities and primary interests of parents of children diagnosed with cancer, the motivations for tweeting about each theme appeared to be different. Similar to the case study on breast cancer survivors using a mailing list as online social support (Høybye et al, 2005), for some participants of this study the act of tweeting about a child’s cancer experience provided an actionable way of coping with the family’s overall experience. However, this wasn’t the case for all. Some parents continued their existing activity of tweeting through their child’s diagnosis with cancer, but eventually found it to be too time consuming. Other parents felt that tweeting was in fact a convenient and time-effective way of keeping friends and family abreast about their child’s experience.

While some parents found Twitter to be an effective medium for raising awareness about childhood cancer, other parents felt that other social media platforms like Facebook for example may have been more useful. Some parents depended on their Twitter network for support during
difficult periods of their child’s cancer experience, while other parents did not feel any comfort in reaching out for support from virtually unknown people despite being empathic about the stories shared by others. While a notable feature of Twitter is its apparent ability to foster world-wide networks of support for cancer survivors and patients across geographic boundaries including strangers rather than existing in-person relationships (Murthy et al, 2011), this did not appear to be a support structure that worked for every family with a child diagnosed with cancer.

Most participants of this study were unanimously motivated to use Twitter for its wide reach of audience and its effectiveness in the ability to share glimpses of their personal experience with childhood cancer in order to raise awareness about the damages caused by childhood cancer, personal opinions about health care and support facilities, as well as drawing attention towards current campaigns and fundraising initiatives related to childhood cancer. While some parents remained highly motivated with their interactions on Twitter towards the common purpose of raising awareness, other parents found that their motivations to use Twitter changed or dwindled over time.

The participants of this research study did not appear to be actively seeking information on Twitter, rather choosing to share information with others and consuming information that they came across arbitrarily. Twitter presents a rather open-ended atmosphere which allows for multi-directional communication among individuals who are a part of informal communities fostered around illness experiences like childhood cancer. The motivations for using Twitter reported by the participants of this study therefore largely focused on the ability to spread messages very quickly to a widespread audience. The reported benefits similarly related to connect with individuals in similar life circumstances and the convenience of being able to come across information that is relevant for their specific circumstances. Aligned with the key themes of conversation identified during analysis for the first research question, parents reported being motivated to use Twitter to raise awareness about childhood cancer, to be engaged in a community that would help them hold on to hope during difficult times, to seek and provide mutual social support while coping with a child’s cancer diagnosis or death, as well as to promote campaigns and fundraising initiatives related to childhood cancer. Some parents reported that these motivations changed over time, and sometimes the benefits of Twitter no
longer applied to their life circumstances, or that they were no longer willing to share their personal experiences in a public sphere.

5.2 Implications for patient and family centered health care

In reference to recommendations made by the Institute of Medicine (IOM) about addressing needs and challenges in the area of information management in cancer care by enhanced patient engagement and empowering patients to drive disruptive innovation within their own health care experience (National Cancer Policy Forum, 2012), there are numerous studies that posit online health communication to be a source of patient generated content that creates a platform to engage patients in contributing towards improving their own health care experience. The key themes of tweets posted by parents of children diagnosed with cancer, as identified in this research study, can certainly be situated within the larger context of patient generated content on the internet leading to insights about understanding priorities and perspectives expressed through tweets. Findings from a similar research study published by Ziebland and Wyke (2012) on the use of Twitter by dementia patients and their family members suggests that the multidimensional participation in the collective creation of health information through activities like blogging or social networking on health topics can influence patients’ health experiences and lead them to understand their role in their own health care management and knowledge building. Considering the key themes of conversation identified in this research study, as well as the reported motivations and benefits of using Twitter as a tool to engage in public discourse related to childhood cancer, health care and social support professionals can use these findings to inform innovative ways of engaging patients and practitioners within the childhood cancer community.

Online health communication research within pediatric patient centered health care delivery can be better informed with an enhanced understanding of the online content created by a new generation of patients and families who are extremely comfortable and inclined to engage in extensive online interactions. Following suggestions by the IOM, understanding the experiences of digitally engaged parents of children diagnosed with cancer as described through tweets can certainly play a role in informing information management research within pediatric cancer care.
5.3 Recommendations for future research

Exploring a viable way to collate and use conversations of parents of children diagnosed with cancer on micro-blogging platforms like Twitter to retrieve trustworthy and authentic feedback about existing cancer care delivery can be suggested as an addition to the findings of this research study as well as a future research opportunity. The potential usage of standardized hash-tags within childhood cancer related tweets to generate easily searchable data that can be organized and analyzed seamlessly can be used as a method to sifting through large amounts of tweets to discover content that maybe considered useful for health care professionals. Future work can also separate tweets from re-tweets to investigate the phenomenon of propagating health information and illness experiences from user to user. And finally, as Twitter is not the only social media platform used by parents of children diagnosed with cancer, further study can be conducted on discussion forums, Facebook, or even Pinterest and Instagram to understand what type of information is shared through images and personal expressions (Robillard et al, 2013).

Despite the known and examined phenomenon of patient generated content on the internet, there is further research needed to understand how parents and families of children diagnosed with cancer continue to become a part of the knowledge creation process through social media (Ziebland, Evans, and Toynbee, 2011; Ziebland & Wyke, 2012; Heilferty, 2009). The key themes of tweets identified in this study as well as the discussion about reported benefits and motivational factors indicate that tweeting about a child’s cancer experience has the potential to play a role in social and emotional support, in addition to being viewed as an information sharing and seeking activity. Further research in examining the role of Twitter as a tool for social and emotional support could potentially allow cancer care professionals and policy makers to understand online patient support services better and design health interventions that are better aligned towards the specific needs of caring for a child with cancer, or for nurses and caregivers providing support to a bereaved family that has lost a child to cancer.
5.4 Limitations of study

5.4.1 Selection bias

All Twitter accounts selected for this study purportedly belong to parents who are currently caring for a child diagnosed with cancer, or have cared for a child with cancer in the past. Self identification information published in the account holder’s public profile was used to identify individuals who met this criterion. Accounts that did not have publicly posted self identification information that met this criterion were excluded. The timing during which tweets were collected for this study could have implications for the type of content expressed by the recruited participants, as well as the specific choice of recruited users. However, participation invitations were sent out at various times during the week as well as on weekdays to ensure a wide range of Twitter users were invited for this study, and that invited users were not limited to a specific geographic location or time zone.

5.4.2 Sample size

The sample size of Twitter accounts selected for this study was not intended for the purposes of reaching generalizable conclusions. The purpose was rather to conduct a qualitative analysis of a phenomenon that exists on Twitter, and to describe findings of the study qualitatively and circumstantially. Due to the inherent selection bias, it would be difficult to assess if the population truly represents the complete set of populations. However, brief snapshots of a wider population that could provide a more generalizable viewpoint were included within analysis to circumvent the limited sample size.

5.4.3 Validity of coding

The scope of this research project was defined to meet the time and resource capacity allotted for a Master’s thesis. Qualitative analysis through categorization and coding of the raw data collected from Twitter as well as from e-mail interviews was conducted by a single researcher. While allowing for additional coders of the qualitative data may have resulted in some variations of the final set of findings, pro-active steps were taken in place of determining statistical inter-coder validity measures. The research supervisors were involved in the process of reviewing
sample data sets within the coding iterations, and modifications were made based on review comments throughout the process.

5.4.4 Trusting social media

The inherent anonymity of users on social media platforms or the internet in general, makes it impossible to verify the authenticity of content and personal identity, or to reach significant statistical correlations in terms of user demographics and social media usage behaviour. This qualitative study however did not intend to authenticate information shared on Twitter by parents of children diagnosed with cancer, rather focused on analysis of content itself. Each recruited participant was considered to a significant part of an overall community, and the content published by the users was considered to be validated by the fact that each user provided informed consent to participate in the study.
Chapter 6
Conclusion

6 Conclusion

The purpose of this research study was to identify the key themes of conversation taking place on Twitter among parents of children diagnosed with cancer, as well as to reveal the reported motivations and benefits expressed by parents about their experience in using Twitter as a tool for sharing their child’s cancer journey. The in-depth analysis of data collected through the means of tweets from recruited parents as well as e-mail interviews conducted with parents led to a contextual understanding of the childhood cancer community that exists on Twitter. Apart from parents and family members of children diagnosed with cancer, this community consists of a wide range of individuals and organizations linked to childhood cancer in varied ways. Analysis of composite profiles was applied to develop representations of “typical” parents of children diagnosed with cancer who tweet about their child’s experience. These composite profiles can be viewed as providing guiding principles when designing health care solutions within a patient centered health care delivery for pediatric oncology care. The key themes of conversations identified within this study can lead to providing an insight into priorities and perspectives of parents of children diagnosed with cancer. While not all parents described their experience of tweeting about their child’s cancer journey to be beneficial, the perspectives obtained from this study certainly suggests that there is an increased need for tapping into the interactions of patients and their family members on social media platforms like Twitter to enhance patient provider relationships within health care delivery, as well as to inform front-line support provided within pediatric oncology care by nursing staff and social support personnel.

6.1 Rigor measures

The qualitative content analysis conducted for the purposes of answering the research questions posed in this research study were largely dependent of subjective interpretation of the perspective of the participants as expressed through tweets, as well as through email interviews. However, following Schutz’s proposed postulate of subjective interpretation within social phenomenology, every effort was made to preserve the participant’s subjective point of view, and the context of the interpretation was always acknowledged in drawing conclusions and
describing results (Schutz, 1967; Leininger 1994; Horsfall et al., 2001; Sandelowski, 2002). Direct quotations from tweets and email interviews were used to support categorizations as much as possible to ensure that the coding is subjectively linked to the context of the raw data as well as to excerpts directly from the quotes of the participants. Using more than one source of data (tweets and e-mail interviews) strengthened the validity of the coding exercise. Although the raw data for this research study will not be accessible to anyone other than the researchers involved due to privacy and ethical concerns, every step of coding and categorizing has been demonstrated methodically and direct quotations from the text has been used wherever possible to maintain transparency of interpretations by using the words as directly expressed by the respondents or participants (Rice & Ezzy, 1999; Patton, 2002; Tobin & Begley, 2004).

Additionally, the purpose of applying a close reading approach was to look beyond Twitter as merely the medium of conversation – rather treat it as a platform seamlessly integrated in an environment where parents of children diagnosed with cancer freely share thoughts and knowledge while seeking support from each other. Although close reading does not aim to produce an individual true meaning of the text, it allows the reader to look beyond the face value of text through a repeated process of demolishing the text and reconstructing it based on a higher understanding or context of the represented conversations (Looy & Baetens, 2003: 7-10).

6.2 Ethics considerations

Ethics approval was obtained from the Research Ethics Board at the University of Toronto as human subjects were involved in this research study. Appropriate care and caution was taken during all e-mail communication with the recruited participants to ensure the child’s health condition as well as the family’s overall emotional state is considered with utmost respect and sensitivity as discussing a child’s experience with cancer may be emotional for the parents contacted to participate in this study. The email interview questions (see Appendix D) did not ask any questions about the child’s health or experiences but focused on the use of Twitter as a medium for communication and conversation. Participants were informed that they do not have to answer any questions if they do not want to. In fact, the reason for using email interviews instead of phone interviews was so that participants can take the time needed to choose the level of detail they wish to provide and decide which questions to answer on their own time, only providing information they are comfortable with sharing.
References


Appendix A Recruitment tweet

[@Twitter_User_name] Would like to use your Tweets for childhood cancer communication research at U of T. Please visit [bit.ly link to Recruitment Message and Informed Consent webpage] for details, Thanks!
Appendix B Recruitment message

Dear Participant,

Thank you for your interest in our research project, and for taking the time to view this message. My name is Sameen (Nuzhat) Rehman and I’m a Graduate student in the Faculty of Information at the University of Toronto. I am conducting research about the usage of Twitter by parents of children diagnosed with cancer, and came across your Twitter account. As you may have noticed from my Twitter profile, I recently lost my daughter to childhood cancer and through this research project, I am trying to reflect on what I learned from my experience of my daughter’s brave journey to conduct research that can potentially demonstrate the role of social media platforms like Twitter in building informal support networks for parents of children diagnosed with cancer. With your help and participation, my aim is to place my research findings within the larger context of contributing towards the existing body of knowledge related to providing an overall family-focused health care experience for families with children diagnosed with cancer.

With your permission, I would like to study your use of Twitter as a part of my research.

I would also like to invite you to participate in a brief e-mail interview to understand how and why you decided to use Twitter to share your experience. This interview should take approximately 30-40 minutes of your time. If you agree to an interview, I will e-mail you a brief set of questions that you can respond to at your convenience. With your consent, I will be reading your Tweets and analyzing your response to the e-mail interview for the purposes of this study. Your name, e-mail address, and your child’s name will be kept confidential and will not be used in any of the analysis or published results. You may choose to give me permission to –

a. Use your Tweets and e-mail interview for the purposes of this study.

b. Use your Tweets only for the purposes of this study, but decline e-mail interview.

Your participation in this research study would be greatly appreciated, and I look forward to your help in making this research study a success. The link below provides more details about the study and gives you information needed to make an informed decision to consent to participate.

[Button to Informed Consent Page]
Thank you.

Sameen (Nuzhat) Rehman
Graduate Student (Master of Information)
Faculty of Information
University of Toronto
1 905 616 3572
sameen.rehman@utoronto.ca
Appendix C Informed consent form

Thank you for volunteering to participate in this study conducted at the Faculty of Information, University of Toronto. The overall goal of this project is to explore the usage of Twitter by parents of children diagnosed with cancer for the purposes of sharing personal experiences as well as communicating with other parents in similar circumstances about their child’s illness experience. The purpose of the proposed research is to draw attention to the practice of online conversations to build informal support networks through social-media platforms.

There are two parts to this study. In the first part, content published on your Twitter account will be analyzed. In the second part, you will be invited to participate in an e-mail interview. You may choose to participate in the first part only, or both parts of the study.

Part 1: If you agree to participate by clicking “I agree to participate in part 1” below, content published on your Twitter account will be analyzed. Your name or your child’s name as published on your Twitter account will not be identified except through a coded ID or pseudonyms in all research findings and reports. The list that connects your real name and your ID will be kept separately from the datasets in password protected and encrypted files in secure locations. Access to this list will be available only to the two researchers (listed below) involved in this study. At any point during the analysis, if you decide that you do not want your Twitter account to be a part of this study – you may notify the researcher and all information related to your account used throughout the duration of the study will be deleted and destroyed. The researcher will notify you once all information has been destroyed.

Part 2: You are also invited to participate in an e-mail interview for this study. This interview should take approximately 30-40 minutes of your time. If you agree to participate in this part of the study by clicking “I agree to participate in part 1 & 2 of the study” below, you will be asked to provide a valid e-mail address for further correspondence. Your e-mail address will be kept confidential and used only for the purposes of corresponding with you. Please note, you may decline participation in the e-mail interview, and participate in Part 1 of the study only. If you choose to participate in the e-mail interview, you may also decline answering one or more of the interview questions if you wish to do so. If you decide after completion of the interview that you
do not want your Twitter account or e-mail interview to be a part of this study – you may notify the researcher, and all of the information you may have provided throughout the duration of the study will be deleted and destroyed. The researcher will notify you once all information has been destroyed.

Contact Information:

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You may also contact the University of Toronto Office of Research Ethics at ethics.review@utoronto.ca or 416-946-3273 if you have any questions about your rights as a participating organization. Please keep a copy of this information letter for your own reference.

If you choose to participate in the e-mail interview, please enter your e-mail address below. Your e-mail address will only be visible by the researcher. If you choose not to participate, you may leave this box blank.

[Text box to enter e-mail address]
[“I agree to participate in Part 1 of the study” button]  [“I agree to participate in Part 1 & 2 of the study” button]

[Back button that redirects to recruitment message in Appendix B]

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Appendix D E-mail interview text

Dear [Name/Twitter User Name],

Thank you for your interest in this project, and for sparing some time to complete this e-mail interview. As described in my initial message on the introductory webpage, the following is a brief set of questions related to your usage of Twitter. It should take you approximately 30-40 minutes to respond to these questions. Please note that your input is very important and highly valued for our research study. Please provide responses to the following questions at your convenience. I would however request that you send me your response by [Date 3 weeks later] in order to incorporate your input effectively in our research study.

You can choose to answer all of the following questions, or answer only those that you are comfortable with. There is no restriction on the length of your answer.

Once again thank you for your time and effort in contributing towards this research study.

Section 1: Choosing Twitter

1. At what stage of [Child’s name]’s diagnosis did you start Tweeting about [his/her] illness experience?
2. Do you use any other online tools (i.e. blogs, Facebook, CarePages etc) to share and discuss [Child’s name]’s experience?
3. Why did you choose Twitter?
4. Have the reasons that you Tweet changed over time?
5. If yes, in what way have your reasons for Tweeting changed?

Section 2: Twitter experience

1. How long have you been Tweeting about [Child’s name]’s cancer experience?
2. Please indicate what types of Twitter feeds you prefer to follow (you can select one or more from the choices below) –
   - Other parents of children diagnosed with cancer
   - Organizations related to childhood cancer advocacy and/or education
   - Childhood cancer fundraiser initiatives
   - Other (please explain)
3. What topics do you usually Tweet about?
4. What topics do typically follow?
5. What prompted you to start Tweeting about [Child’s name]’s story?
3. Has Tweeting and following Tweets from other parents with children diagnosed with cancer played a role in your personal journey of coping with [Child’s name]’s overall experience?
4. If Yes, how has Tweeting and following other parent’s Tweets helped you cope? If No, did you anticipate that it would help you cope?
8. During the time that you’ve been Tweeting about [Child’s name]’s journey, how would you define your relationship with other parents Tweeting about their children’s cancer experience?
9. What role does your Twitter interaction with other parents with children diagnosed with cancer play in your family’s overall support network related to [Child’s name]’s cancer experience?
10. Thinking about your whole experience since your child was diagnosed, can you tell us a story about one particular time when Tweeting or reading Tweets has been particularly significant for you or your family?

**Section 3: Additional comments**

If you have any additional comments that you think would be helpful for the purposes of this study, please list comments here.
## Appendix E Composite profile forming matrix

<table>
<thead>
<tr>
<th>Characteristics Category</th>
<th>Parent Profile A</th>
<th>Parent Profile B</th>
<th>Parent Profile C</th>
<th>Parent Profile D</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent’s Name</td>
<td>Jill</td>
<td>Jack</td>
<td>Jane</td>
<td>John</td>
</tr>
<tr>
<td>Parent’s Twitter user name</td>
<td>@TamarasMommy</td>
<td>@TimsDaddy</td>
<td>@Hope4Lucy</td>
<td>@LiamsGoldenRibbon</td>
</tr>
<tr>
<td>Child’s name</td>
<td>Tamara</td>
<td>Tim</td>
<td>Lucy</td>
<td>Liam</td>
</tr>
<tr>
<td>Child’s stage in treatment</td>
<td>Currently in treatment, diagnosed 11 months ago.</td>
<td>In remission. However there is a possibility of relapse.</td>
<td>Child passed away during treatment.</td>
<td>Child passed away as there was no further treatment possible.</td>
</tr>
<tr>
<td>Location of child</td>
<td>In and out of hospital</td>
<td>At home</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>When did you start Tweeting</td>
<td>Had a Twitter account before child was diagnosed, and Tweeted regularly.</td>
<td>Started tweeting during child’s first hospital stay.</td>
<td>Was an active Twitter user, but stopped tweeting while child was being treated for cancer. Started tweeting again about child’s cancer experience after child died.</td>
<td>Started tweeting after child’s diagnosis</td>
</tr>
<tr>
<td>Characteristics Category</td>
<td>Parent Profile A</td>
<td>Parent Profile B</td>
<td>Parent Profile C</td>
<td>Parent Profile D</td>
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<tr>
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<td>-----------------</td>
</tr>
<tr>
<td>Updates</td>
<td>Account used primarily to provide updates about child's condition.</td>
<td>Provides frequent updates and Tweets about child's daily life – which includes achievements, things the child says or does, treatment updates etc. - expresses thankfulness for child's life and child's accomplishments.</td>
<td>Occasionally tweets about happy memories of child - sometimes accompanied by family pictures.</td>
<td>Occasionally tweets about memories of child while child was in treatment and uses images of child. Tweeted about child’s death announcement.</td>
</tr>
<tr>
<td>Fundraising</td>
<td>Occasionally retweets links to fundraising initiatives shared on Twitter by others.</td>
<td>Passionately Tweets about own fundraising initiative (raising funds for own child’s treatment) as well as Retweets other fundraising initiatives.</td>
<td>Passionately Tweets about fundraising initiatives led by an organization created in memory of Lucy. Also shares tweets about other charitable and advocacy initiatives - childhood cancer related and other childhood disease related.</td>
<td>Frequently retweets fundraising initiatives posted by others.</td>
</tr>
<tr>
<td>Childhood cancer awareness</td>
<td>Tweets personal perspective on how childhood cancer affects a child's life. Occasionally retweets other parents' perspective.</td>
<td>Tags (mentions) celebrities and organizations to promote childhood cancer awareness.</td>
<td>Posts news clips and videos about childhood cancer awareness and any information about</td>
<td>Tweets about life after losing a child to cancer, and the devastation caused to child and family.</td>
</tr>
<tr>
<td>Characteristics Category</td>
<td>Parent Profile A</td>
<td>Parent Profile B</td>
<td>Parent Profile C</td>
<td>Parent Profile D</td>
</tr>
<tr>
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</tr>
<tr>
<td>Childhood cancer advocacy</td>
<td>Tweets and retweets about lobbying for allocating sufficient childhood cancer research dollars by the Government, as well as for bereavement support.</td>
<td>Tweets and retweets about volunteer experience with organization that is involved with raising funds for childhood cancer research and advocacy.</td>
<td>Created own organization in memory of child for childhood cancer advocacy and fundraising. Tweets frequently about this organization.</td>
<td>Is not directly involved in advocacy, but frequently retweets initiatives taken by other parents.</td>
</tr>
<tr>
<td>Using images of child</td>
<td>Posts pictures of own child to show small steps in treatment success.</td>
<td>Does not post images of child.</td>
<td>Posts pictures of child while in treatment treatment as well as when child was well.</td>
<td>Only posts pictures of child where child looks happy and well.</td>
</tr>
<tr>
<td>Interacting with other parents of children diagnosed with cancer</td>
<td>Does not interact much with other parents of children diagnosed with cancer. Occasionally retweets posts from other parents.</td>
<td>Heavily followed by other parents of children diagnosed with cancer, and follows them also. Frequent tweets exchanged and responded to. Also retweets updates from other parents.</td>
<td>Does not interact much with other parents of children diagnosed with cancer. Occasionally retweets from other parents.</td>
<td>Is very diligent in posting Tweets for recently bereaved parents as well as accounts of children going through a rough stage in treatment.</td>
</tr>
<tr>
<td>Using other social media platforms</td>
<td>Does not use any other social media platform.</td>
<td>Maintains a very detailed blog about child’s cancer experience, and occasionally Tweets links to</td>
<td>Maintains Facebook in memory of child.</td>
<td>Maintained a Caringbridge page while child was in treatment.</td>
</tr>
<tr>
<td>Characteristics Category</td>
<td>Parent Profile A</td>
<td>Parent Profile B</td>
<td>Parent Profile C</td>
<td>Parent Profile D</td>
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<tr>
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</tr>
<tr>
<td>Personal emotions related to child's cancer experience</td>
<td>Expresses frustration over lack of funding and support for childhood cancer.</td>
<td>Expresses relief, joy and thankfulness, but also expresses cautiously knowing that cancer can relapse.</td>
<td>Does not express much about personal emotions related to child's death on Twitter.</td>
<td>Twitter account as a means to document letting things go and moving into a future without child.</td>
</tr>
<tr>
<td>Reflection of personal life in Tweets</td>
<td>Does not talk about personal life other than topics related to child’s cancer experience, and occasionally posts religious thoughts.</td>
<td>Is a sports enthusiast and frequently shares news articles related to sports events and interesting sports related facts.</td>
<td>Only mentions personal involvement in fundraising and charity initiatives.</td>
<td>Posts about activities with other living children.</td>
</tr>
<tr>
<td>Thoughts about using Twitter</td>
<td>Feels that Tweeting takes up a lot of time that should be devoted to spending with child, and therefore is thinking about shutting down Twitter account.</td>
<td>Thinks Twitter helps in reaching people far and wide and therefore believes this will help spread the word about childhood cancer awareness.</td>
<td>Believes in sharing positivity through tweeting about inspirational quotes that maybe uplifting to other families, and intends to support hopes for other families, but is not yet ready to actively interact with other families as it might be too painful.</td>
<td>Helps connect with other parents who have walked the same path, and tries to make sense of the experience his family has gone through by reading about glimpses of experiences of other families.</td>
</tr>
<tr>
<td>Characteristics Category</td>
<td>Parent Profile A</td>
<td>Parent Profile B</td>
<td>Parent Profile C</td>
<td>Parent Profile D</td>
</tr>
<tr>
<td>----------------------------------</td>
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<td>----------------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Support network on Twitter</td>
<td>Twitter features within support network, but not to a great degree</td>
<td>Twitter is important in terms of providing access to a worldwide network of similar sufferers.</td>
<td>This relationship is not part of my day-to-day support from friends, family, Community, the doctors and I was wary of it becoming too time-consuming – that's dangerous in terms of my overall duty as primary carer for my family unit.</td>
<td>I haven't built any relationships over twitter. Several parents I follow I already knew.</td>
</tr>
<tr>
<td>Role of Twitter on personal journey with childhood cancer</td>
<td>While the story for each child is always unique, there are countless common threads that run through each of their journeys. Being in contact with others help her cope in the long run.</td>
<td>Tweeting and raising awareness has certainly helped me try and process what happened/is happening to our family. We could never get to the parental support evenings at the hospital because it was always in the evening, an hours drive each way away &amp; we have two other children as well as the super-sick child.</td>
<td>While it usually helps, there have been sometimes when I got somewhat attached to the child and family, though I never met them. As often is the case, the child doesn't make it through their treatments, thus opening the wounds of the loss of Darrel all over again.</td>
<td>Prefers to follow organizations who work with childhood cancer research and is deeply interested in advancements made in childhood cancer care. Feels the need to be involved in childhood cancer advocacy by providing his input wherever possible based on personal experience. Helps him cope.</td>
</tr>
<tr>
<td>Characteristics Category</td>
<td>Parent Profile A</td>
<td>Parent Profile B</td>
<td>Parent Profile C</td>
<td>Parent Profile D</td>
</tr>
<tr>
<td>--------------------------</td>
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<td>------------------</td>
<td>------------------</td>
</tr>
<tr>
<td>Primary reason for Tweeting</td>
<td>Providing updates to friends and family.</td>
<td>Hoped to reach a wider group of people including celebrities who may get involved with our fundraising.</td>
<td>I had thought it would reach a wider group of people including celebrities who may get involved with our fundraising.</td>
<td>it is much easier to have current information and updates on our activities posted than to reopen the account for changes several times a day/week. Being able to post from my smartphone/tablet are advantages too.</td>
</tr>
</tbody>
</table>
Appendix F Tweet analysis – Complete list of codes after open coding

<table>
<thead>
<tr>
<th>Code Label</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>RT</td>
<td>This code identifies whether this is a Retweet. This is a Tweet from another person highlighted by the owner of the Twitter account being analyzed.</td>
</tr>
<tr>
<td>Picture of child</td>
<td>This code identifies whether a picture of the child has been shared within the Tweet.</td>
</tr>
<tr>
<td>Supporting hope and positivity</td>
<td>This code identifies whether an image has been shared within the Tweet - just an image, or an image with text/inspirational quote.</td>
</tr>
<tr>
<td>through images</td>
<td></td>
</tr>
<tr>
<td>Other picture shared</td>
<td>This code identifies whether an image has been shared which is not an image of a child, or an inspirational image. Ex. Image of other children/siblings, image of events unrelated to the child etc.</td>
</tr>
<tr>
<td>Link shared</td>
<td>This code identifies whether a link has been shared within the Tweet.</td>
</tr>
<tr>
<td>Type of Link</td>
<td>If a link has been shared within the Tweet, this code describes what type of link was shared. Ex. Local newspaper article about the child's experience, something related to personal interest of the parent, etc.</td>
</tr>
<tr>
<td>(blog/facebook/news/article)</td>
<td></td>
</tr>
<tr>
<td>Referring to Facebook</td>
<td>This code identifies whether the Tweet refers to a Facebook page that is related to the child's cancer experience. Ex. Facebook fundraising page, event page, or a page that provides updates about the child.</td>
</tr>
<tr>
<td>Referring to blog</td>
<td>This code identifies whether the Tweet refers to a blog maintained by the parent (or friend/other family member) about the child’s cancer experience.</td>
</tr>
<tr>
<td>Referring to other platform</td>
<td>This code identifies whether the Tweet refers to some other web platform that is used during the child’s cancer experience. Ex. Caringbridge, carepages</td>
</tr>
<tr>
<td>Code Label</td>
<td>Description</td>
</tr>
<tr>
<td>----------------------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>etc.</td>
<td></td>
</tr>
<tr>
<td>Non cancer Conversation/Response</td>
<td>This code identifies whether the Tweet is a part of a regular conversation that is unrelated to the child's cancer experience.</td>
</tr>
<tr>
<td>Cancer related conversation/Response</td>
<td>This code identifies whether the Tweet is related to the child's cancer experience, or about childhood cancer in general. It could be a part of a conversation, or a standalone Tweet.</td>
</tr>
<tr>
<td>Mentioning a person</td>
<td>This code identifies whether a Tweet mentions a person using the Twitter @ sign. This signifies the Tweet is trying to draw someone's attention.</td>
</tr>
<tr>
<td>Mentioning an organization</td>
<td>This code identifies whether a Tweet mentions a charitable organization using the Twitter @ sign. This signifies the Tweet is trying to draw attention of an organization, or promoting something related to that organization.</td>
</tr>
<tr>
<td>Mentioning a celebrity</td>
<td>This code identifies whether a Tweet mentions a celebrity using the Twitter @ sign to draw attention of that celebrity to raise childhood cancer awareness.</td>
</tr>
<tr>
<td>Mentioned by other user</td>
<td>This code identifies whether this Tweet is from another user, but mentions the parent to whom this Twitter account belongs.</td>
</tr>
<tr>
<td>Cancer awareness</td>
<td>This code identifies whether this Tweet is in general related to raising awareness about childhood cancer.</td>
</tr>
<tr>
<td>Cancer awareness by mentioning own child</td>
<td>This code identifies whether this Tweet mentions own child's story to raise awareness about childhood cancer.</td>
</tr>
<tr>
<td>Update</td>
<td>This code identifies whether this Tweet is providing an update about the child's condition to friends and family.</td>
</tr>
<tr>
<td>Fundraising</td>
<td>This code identifies whether this Tweet intends to invite people to donate or raise funds for the child's treatment or for childhood cancer research in</td>
</tr>
<tr>
<td>Code Label</td>
<td>Description</td>
</tr>
<tr>
<td>------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Supporting hopes and spreading positivity</td>
<td>This code identifies whether this Tweet is inspirational and supportive of other parents in similar circumstances - an uplifting quote about life in general or about facing difficult circumstances.</td>
</tr>
<tr>
<td>Quote related to cancer</td>
<td>This code identifies whether this Tweet is an uplifting quote related to child's cancer experience, hope for a cure, general inspirational quote about battling childhood cancer, etc.</td>
</tr>
<tr>
<td>Cancer related hashtag</td>
<td>This code identifies whether a cancer related hashtag has been used within the Tweet.</td>
</tr>
<tr>
<td>Note</td>
<td>This code was used to keep a note/description about something unusual or interesting about the particular tweet.</td>
</tr>
</tbody>
</table>
## Appendix G E-mail analysis – Start list of codes

<table>
<thead>
<tr>
<th>Code Label</th>
<th>Interview Question</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Choosing Twitter</strong></td>
<td></td>
</tr>
<tr>
<td>Stage of diagnosis</td>
<td>At what stage of child’s diagnosis or cancer journey did the parent start</td>
</tr>
<tr>
<td></td>
<td>Tweeting</td>
</tr>
<tr>
<td>Other online platform used</td>
<td>What other online tools are used by parent to share child’s experience</td>
</tr>
<tr>
<td>Reason for choosing Twitter</td>
<td>Why did the parent choose Twitter as a platform to share child’s experience</td>
</tr>
<tr>
<td>Reason changing over time</td>
<td>Has the initial reason for choosing Twitter changed over time</td>
</tr>
<tr>
<td><strong>Twitter experience</strong></td>
<td></td>
</tr>
<tr>
<td>Duration</td>
<td>How long has parent been Tweeting about child’s cancer experience</td>
</tr>
<tr>
<td>Twitter feeds followed</td>
<td>Types of Twitter feeds/accounts typically followed by user</td>
</tr>
<tr>
<td>Topics followed</td>
<td>Topics/discussions/issues that the parent is interested in and follows regularly</td>
</tr>
<tr>
<td></td>
<td>within Twitter</td>
</tr>
<tr>
<td>Tweet topics</td>
<td>Typical topics parent usually Tweets about</td>
</tr>
<tr>
<td>What prompted Tweeting</td>
<td>What prompted user to start Tweeting about child’s cancer experience</td>
</tr>
<tr>
<td>Role in personal journey</td>
<td>Has Tweeting and following Tweets from other parents with children diagnosed with</td>
</tr>
<tr>
<td></td>
<td>cancer played a role in your personal journey of coping with your child’s</td>
</tr>
<tr>
<td></td>
<td>overall experience?</td>
</tr>
<tr>
<td>Code Label</td>
<td>Interview Question</td>
</tr>
<tr>
<td>----------------------------------</td>
<td>----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Relationship with other parents on Twitter</td>
<td>Description of relationship with other parents of children diagnosed with cancer – relationship established through Tweeting</td>
</tr>
<tr>
<td>Role in family’s support network</td>
<td>What role does your Twitter interaction with other parents with children diagnosed with cancer play in your family’s overall support network related to your child’s cancer experience?</td>
</tr>
<tr>
<td>Significant experience</td>
<td>Thinking about your whole experience since your child was diagnosed, can you tell us a story about one particular time when Tweeting or reading Tweets has been particularly significant for you or your family?</td>
</tr>
<tr>
<td>Additional comments</td>
<td>Additional space for respondent to add closing comments, or personal insights that they may think can potentially inform this research study.</td>
</tr>
</tbody>
</table>