Title: Motives for sharing illness experiences on Twitter: Conversations of parents with children diagnosed with cancer

Authors:

Sameen Rehman
Faculty of Information
University of Toronto
140 St. George St.
Toronto, Ontario, Canada M5S 3G6

* Kelly Lyons
Faculty of Information
University of Toronto
140 St. George St.
Toronto, Ontario, Canada M5S 3G6

Rhonda McEwen
University of Toronto Mississauga
Institute of Communication, Culture, Information and Technology
3359 Mississauga Road North
Mississauga, Ontario, Canada L5L 1C6

Kate Sellen
Strategic Innovation Lab (sLab)
OCAD University
100 McCaul Street
Toronto, Ontario, Canada M5T 1W1

* Corresponding Author

Author Bios:

Sameen Rehman is an alumni of the University of Toronto Master of Information Program, graduating in 2014. Her major area of research was focused on using social media (specifically Twitter) as a means for sharing illness experiences within the childhood cancer community. She is currently working as a Business Intelligence professional in the pharmaceutical industry.

Kelly Lyons is an Associate Professor in the Faculty of Information at the University of Toronto. Prior to joining the Faculty of Information, she was the Program Director of the IBM Toronto Lab Centre for Advanced Studies (CAS). Her current research interests include service science, social media, and collaborative work. Currently, she is focusing on ways in which social media can support human-to- human interactions in service systems. Kelly has co-authored a number of papers, served on program committees for conferences, given many keynote and invited

presentations, and co-chaired several workshops. She has been the recipient of an NSERC Discovery Grant, an NSERC Collaborative Research and Development Grant with SAP, and an IBM Smarter Planet Faculty Innovation Grant, has received funding through the GRAND Networks of Centres of Excellence (NCE) and has been the recipient of two NSERC Engage Grants (one with Sciencescape and one with Dell). Kelly holds a cross- appointment with the University of Toronto's Department of Computer Science, is a member of the Executive Committee of the University of Toronto's Knowledge Media Design Institute, and is an IBM Faculty Fellow. From 2008 to 2012, she was a Member-at-Large of the ACM Council and a member of the Executive Council of ACM-W. Kelly is very interested in promoting Women in Technology initiatives and has given several presentations to young people and teachers on this topic.

Rhonda McEwen is an associate professor at the Institute of Communication, Culture, Information and Technology and at the iSchool, at the University of Toronto. She holds an MBA in IT from City University in London, England, an MSc in Telecommunications from the University of Colorado, and a PhD in Information from University of Toronto. Dr. McEwen has worked and researched digital communication media for 15 years, both in companies providing services and in management consulting to those companies. Her research and teaching centre around information practices involving new media technologies - with an emphasis on mobile and tablet communication, new media, social networks, and sensory information processing. CBS 60 Minutes journalists covered McEwen's research in 2012 & 2013, and she has recent publications in Information, Communication & Society, Computers and Education, Learning & Instruction, New Media and Society, and Library and Information Science Research journals.

Kate Sellen has a Master's degree in Information Design from Georgia Institute of Technology, a Bachelor's of Science and Master of Research from University College London, and a PhD in Human Factors in Industrial Engineering from University of Toronto. Her research broadly addresses design thinking and human factors for challenges in healthcare with a focus on resilience and creativity in innovation for safety critical and distributed healthcare. Her research aligns with healthcare system goals of enhancing the efficient delivery of healthcare, preventing iatrogenic events, and assisting patients and home caregivers to effectively manage home care. Addressing these goals necessitates a human centred approach to design and research, sensitivity to healthcare as a system, knowledge of emerging and current technology trends, and attention to potential barriers and facilitators to leading innovation and change. Kate leads the teaching of human centered approaches for OCADU's Strategic Foresight and Innovation program (SFI OCADU), and coaches student teams for the Hult Prize and Rotman Design Challenge.

ABSTRACT: A patient and family-centered approach in pediatric health care is important because 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 increasingly turning to the internet to find and actively share information about their child's health care. 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 suggests that there is a need to better understand the motives for using Twitter for sharing content about a child's cancer experience. Furthermore, there is a lack of theoretical frameworks for characterizing those motives. In this paper, we identify key themes of tweets posted by parents of children diagnosed with cancer and align those themes with motives inspired by the well-studied Everyday Life Information Seeking framework. We propose a new motive in addition to those associated with the framework and suggest that information can be shared for endogenous reasons as well as to meet the needs of others. This paper contributes an increased understanding of motives for sharing information about a child's cancer journey and extends a theoretical framework for building further knowledge in this area.

Introduction

Social media websites play an empowering role in allowing patients and family members to interact with others, search for health and wellness related information, as well as to create and share their own content on the internet (Hawn, 2009; Heilferty, 2009; Kaplan, 2012; LaPointe, Ramaprasad, & Vedel, 2014). The networks fostered on social media websites provide a new approach for discussing illness experiences and medical conditions outside more traditional settings such as a healthcare provider's office (Randeree, 2009; Sarasohn-Kahn, 2008). A survey conducted in the United States in 2008 revealed that people use the internet for health and wellness related information more frequently than seeking information from a physician (Elkin, 2008; Sarasohn-Kahn, 2008).

In paediatric health care, the patient is a child. The child's family is his or her foundation of strength and support (Eichner, 2003; Holm, Patterson, & Gurney, 2003). Parents and family members depend on knowledge and information from individuals in similar circumstances in addition to support from healthcare professionals during the difficult and emotionally strenuous experience of caring for a severely ill child. Cancer has continued to be the leading disease-related cause of death among children and the rates of diagnosis of childhood cancer has increased over the past few decades (American Cancer Society, 2016; Ellison & Janz, 2015). 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 with cancer.

While there has been research into the phenomenon of patients and family members, including parents of children diagnosed with cancer, connecting on social media websites to share health related information and personal experiences (Heilferty, 2009), there remains a need for further theoretical, methodical and scientific bases to understand the impact of online accounts of personal

experiences shared by patients and their family members (Fernandez-Luque, Elahi, & Grajales, 2009; Hawn, 2009; Ziebland & Wyke, 2012).

We are interested in examining how existing theories can characterize the ways in which parents of children with cancer make use of social media tools. Specifically, in this study we use the theoretical lens of information seeking in everyday life (Savolainen, 1995) to analyse how parents of children with cancer use Twitter as an information seeking and sharing tool. Despite its rapid growth - currently over 310 million monthly active users (Twitter, 2016) - using Twitter as an online illness narrative tool used by parents of children diagnosed with cancer, is a relatively unexplored area of research. Social media platforms such as Twitter, however, are viewed by healthcare and communication researchers as tools to empower patients and their families in managing their activities related to seeking and exchanging information (Hawn, 2009; Wiener, Crum, Grady, & Merchant, 2012).

Information seeking and sharing has been studied from the perspectives of work related settings (Ellis, 1989; Leckie, Pettigrew, & Sylvain, 1996), education and library settings (Kuhlthau, 1993), as well as everyday life non-work related settings (Johnson, 1997; Savolainen, 1995; Wilson, 1999). Information needs and seeking behaviour within health related settings, particularly in cancer care, has been the subject of study including descriptive studies that use qualitative and quantitative methods of analyses (Leydon et al., 2000; Rees & Bath, 2001). A detailed literature review conducted by Marton and Choo (2012) on theory-driven studies of internet health information seeking strongly suggested the need for exploring multidisciplinary frameworks to capture the complexity of online health information behaviour. We have chosen Savolainen's framework of Everyday Life Information Seeking (ELIS) (Savolainen, 1995; Savolainen, 2007) to characterize how parents with children diagnosed with cancer use Twitter as an online social

media tool to seek and share information. Specifically, we used the ELIS framework to identify dominant themes of tweets posted by parents of children diagnosed with cancer. We chose this particular framework as it conveys a relationship between the "way of life" and "mastery of life" through the social context within which people engage in problem solving behaviour when encountering critical incidents. In the context of this study, dealing with life circumstances following a child's diagnosis with cancer has been viewed as an incident that requires pragmatic problem solving in terms of dealing with the new circumstances of everyday life. 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 of information. In this paper, we propose an extension to Savolainen's framework for the study of online health information behaviour and we add new knowledge about the role or Twitter within the childhood cancer community.

Related Work

A research study related to the role of blogs written by parents of children diagnosed with cancer provides extensive description of how parents foster "peer" relationships through illness narratives on the internet (Heilferty, 2009). The research findings of the study are presented in terms of consequences of blogging about a child's cancer experience as well as describing the interaction between an individual posting blog entries and individuals posting comments on the blog. The consequences of a parent blogging about a child's cancer experience were found to be both positive and negative. 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 to blog which can lead to strained relationships.

While the research findings suggest that reading and incorporating illness blogs into health care can enhance the relationship between the patient and the health care provider in the context of paediatric oncology, an increasing need was revealed to further characterize how parents share and exchange information online through different "computer-mediated" platforms when a child is diagnosed with cancer. Heilferty's (2009) study suggests the opportunity to develop a theory of online communication during illness based on future research focused on other online media used by parents of children diagnosed with cancer. While Heilferty's study provides an extensive analysis of the phenomenon of parents of children diagnosed with cancer sharing content on the internet through blog posts, there were a few other studies in the area of social media tools used by patients and family members.

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. The study evaluated comments posted on publicly available YouTube videos to characterize the type of personal and medical information shared. The findings from the study identified issues related to patient risks and ethical considerations due to sharing health related information in a public forum. 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. The study revealed that a large number of tweets included links to external websites primarily related to news and health information. The major theme of discussion appeared to be related to recent research findings about prediction and risk management for Alzheimer's. The researchers used these results as the basis for a recommendation for further research regarding the potential of using Twitter as a "tool for multi directional engagement" within the dementia research community.

Social media websites have also been viewed as crowdsourcing platforms where clinicians and patients can collaborate to manage disease outbreak and predict pandemics (Purvis, 2012; Ritterman, Osborne, & Klein, 2009), a space where cancer patients can collectively identify treatment options through finding information about clinical trials (Chretien et al., 2011) as well as a closed group 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). Despite the growing body of descriptive literature related to the role of social media in seeking and sharing health-related information within patient networks and communities, the application of formal theoretical frameworks to the phenomenon of non-work related experiences have been relatively unexplored, in particular within the context of sharing illness experiences.

The Everyday Life Information Seeking (ELIS) framework introduced by Savolainen, provides a theoretical approach to analyse the phenomenon of sharing and receiving information in a social non-work context. One of the key concepts in the ELIS framework is the 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.

Savolainen (1995) describes the way of life to be the series of choices people have to make in everyday life and posits that 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, p. 264). In the context of our 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. 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 (2007) identifies three motives for sharing information in everyday life situations -

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 identification of these motives emerged from an empirical analysis of interviews with 20 environmental activists in Finland in 2005 and provide a structural approach for describing and categorizing the activity of sharing information within the context of everyday life circumstances.

Savolainen (2007) suggests that people are primarily prone to share information with others out of a sense of goodness or kindness. People also tend to seek and share information that they know will be valuable to others, and in some situations individuals feel the need to share information when they are placed in a position of authority.

The purpose of our study is to establish the dominant themes of tweets posted by parents of children diagnosed with cancer and to situate the themes within a theoretical framework that describes the phenomenon of information sharing within a non-work context. We have chosen to align the key themes of tweets posted by parents of children diagnosed with cancer within the motives of sharing information as described by Savolainen (2007), and in doing so, to also explore applicability or potential gaps in this alignment.

Research Methodology

We conducted a qualitative analysis of the content of 1700 tweets from the Twitter accounts of 15 recruited participants, all parents of children diagnosed with cancer. The tweets were coded independently by two researchers following a predefined codebook that used Savolainen's (2007) motives as a guide. Each researcher coded every tweet. The inter-coder reliability was calculated using Krippendorf's alpha with a value of 0.97 and 99.58% agreement.

Participants

Participants for this study were parents of a (living or deceased) child diagnosed with cancer at any age up to the age of 19 with an active Twitter account (tweeted at least once in the 7 days prior to recruitment). Although childhood cancer is typically considered within the age range of new-borns to 14 years old, adolescents are also typically treated by paediatric oncologists; therefore, we considered the larger age range (American Cancer Society, 2016; Cancer.Net, 2014).

Recruitment

An initial search for hashtag #childhoodcancer was used to identify a list of current tweets on the topic. The self-identification information provided on the Twitter accounts associated with the tweets retrieved by this search were examined to identify accounts of parents with children

diagnosed with cancer. A publicly viewable recruitment tweet was sent to the initially-identified account holders, followed by an introductory message explaining the details of the research project and inviting participants to provide consent for the publicly available content published on their Twitter account to be analysed for the purposes of this research study. 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, 15 individuals agreed to participate in the study and provided informed consent to analyse their tweets from a total of 17 Twitter accounts.

Analysis

Following Schutz's (1967) proposed postulate of subjective interpretation within social phenomenology, the collected dataset of 1700 tweets were analysed with an effort to preserve the participant's subjective point of view. The context of the interpretation was consistently acknowledged in drawing conclusions and describing results (Horsfall, Byrne-Armstrong, & Higgs, 2001; Leininger, 1994; Sandelowski, 2002; Schutz, 1967). Direct quotations from tweets were used to support categorizations as much as possible to ensure that the coding is subjectively linked to the context of the raw data. The raw data for this research study will not be accessible to anyone other than the researchers involved due to privacy and ethical concerns. The final set of code categories has been demonstrated in this paper with direct quotations listed as sample tweets to maintain transparency of interpretations by using the words as directly expressed by the respondents or participants (Patton, 2002; Rice & Ezzy, 1999; Tobin & Begley, 2004).

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. Brief snapshots of a wider population that could provide a more generalizable viewpoint were included within analysis to circumvent the limited sample size. It was therefore necessary to select random datasets of tweets to ensure wider coverage of the phenomenon being examined.

The website randomizer.org was used to generate four random one-week timeframes within each of the past four months starting from the four selected weeks were collected for analysis. Web-based Twitter analytics tool Twitonomy (http://www.twitonomy.com/) was used to download a snapshot of tweets from each user within the specified time frames directly into Excel files. The number of extracted tweets varied from a low of 132 to a high of 3,248 for each participant based on how often they tweeted during the selected date ranges. Following from the approaches in similar qualitative studies of Twitter data (Lalonde, 2011; Robillard, Johnson, Hennessey, Beattie, & Illes, 2013), we selected 100 tweets at random from each account for the purposes of detailed content analysis, resulting in a final dataset of 1700 tweets.

To develop the codebook, we selected an initial set of 25 tweets. The codebook was inspired by existing theory of information sharing in everyday life situations, and guided by literature review of existing qualitative research studies (Moreno, Egan, & Brockman, 2011). Two coders worked together in applying a deductive approach (Elo & Kyngäs, 2008) to categorize the initial tweets into Savolainen's (2007) three motives of information sharing. Some tweets were aligned with more than one motive. The tweets associated with each of the three motives were further analysed by the coders together to identify more granular categorizations.

Each coder then independently coded an additional set of 100 tweets to validate and modify the initial categorizations. Disagreements between coders were addressed on a case by case basis, and resolved through repeated coding of this dataset followed by discussion. The coders agreed upon a final set of 33 codes. These 33 codes were formally defined in a codebook which was used to categorize the complete set of 1700 tweets. The content of each tweet was then analysed independently by both coders and each tweet was categorized under one or more of the 33 codes.

The coders lastly worked together to group the 33 codes into high-level themes. The high-level themes and codes within each theme are presented in detail in the Results section along with sample tweets in each code within the themes.

Results

The detailed analysis conducted in this study revealed seven major high-level themes:

    (1) Sharing details about child's cancer experience

    (2) Providing updates about child's treatment

    (3) Sharing childhood cancer related facts

    (4) Raising awareness

    (5) Promoting campaigns and fundraising

    (6) Being supportive

    (7) Posting about personal interests and casual conversations

In the following sections we describe each of the seven themes and the codes within each theme. We also provide sample tweets. Names and Twitter user names have been masked to protect the privacy of the participants of this study. For each theme, we provide a table (Tables 1 through 7) that includes the codes identified within that theme (left hand column) and, a single tweet for each code as an example of tweets that were labelled with the corresponding code (right hand column).

Note that some themes are associated with as few as two codes and others are associated with as many as thirteen codes.

Theme 1: Sharing details about child's cancer experience

Parents shared details about many aspects of their child's cancer journey including experiences directly related to the child's treatment as well as regular day to day experiences unrelated to the child's cancer journey. Parents tweeted about details of side effects experienced by the child - like hair loss, dementia, and vivid details of how the child's condition deteriorated over the months following diagnosis. Some examples include tweets about 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 brief snapshots of the family's overall experience in living with and caring for a child with cancer.

Table 1. Theme: Sharing details about child's cancer experience (Sample tweets)

Code	Example
Sharing own child's cancer journey through images	*[child] had a platelett transfusion this evening. Nurses were so proud to see her so well. Weight now 14.85kg <link to image>*
Sharing own child's cancer journey through text descriptions	*[child] is doing really well and feeling great! She starts 2 weeks of radiation on Tuesday. Pls pray for minimal side-effects*
Sharing details about every day activities	*Day6: Eating breakfast in our screened room. [child] making me french toast with fresh raspberries!*
Child's major achievements (participation in sports, awards, treatment milestones etc)	*A yr ago [child] was recovering from having port put in his chest.2nite playing basketball #pray4[child]*

Theme 2: Providing updates about child

Some of the parents used Twitter to provide updates to friends and family about their child's progress through treatment, or to provide updates during long hospital stays and critical moments in treatment. There were also examples of parents tweeting about the death of their child, 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 cancers similar to their own child. Some parents also re-tweeted updates posted about other children.

Table 2. Theme: Providing updates about child (Sample tweets)

Code	Example
Updates about own child's treatment	*[child] yesterday got moved to intensive care due to fluid on her lungs,not been able to breathe.she is on a ventalator and on many meds*
Sharing / re-tweeting updates related to other children	*RT @[parent] @[another parent] [child] will be making the big journey to Florida on Monday with her family to undergo Proton Beam Therapy.*

Theme 3: Sharing childhood cancer related facts

Some tweets concerned the long term side effects of childhood cancer as experienced by the child, as well as information and links about how to deal with side effects such as hair loss. Some parents chose to share informative news articles and online posts. Information about clinical trials and innovative or alternative treatment options are also shared through tweets and re-tweets.

Table 3. Theme: Sharing childhood cancer related facts (Sample tweets)

Code	Example
Sharing childhood cancer related images and/or video	*As the royal baby is born 7 kids in this country will die from cancer today. Circle of life? Why does it have to be? [link to an image with childhood cancer related statistics]*
Posting link to other Social Media sites/posts related to childhood cancer related facts	*Please ask your rep to support this bill named in honor my daughter before it happens to you – [link to Facebook page with childhood cancer related facts and statistics]*
Sharing links to websites that provide childhood cancer related facts	*Childhood cancer, what needs to change. #childhoodcancer [link we informational website]*
Directly tweeting about childhood cancer related facts	*Each year, more than 160,000 children are diagnosed with #cancer worldwide. About 90,000 die from the disease. R u #aware? ..R u #helping?*

Theme 4: Raising awareness

Raising awareness about childhood cancer was found to be one of the key themes in the tweets we analysed. A parent tweeted vivid descriptions and photos to show the stark changes in her child's physical appearance in order to raise awareness about the effects of childhood cancer. Some parents tweeted 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 was reaching out to celebrities and popular organizations (using the "@" mention symbol) requesting them to share their story to gain a larger audience for awareness.

Hashtags are also used to raise awareness within Twitter, and the overall subject area of childhood cancer has a number of popularly-used and defined hashtags (e.g., "#ChildhoodCancer, #childhoodcancerawareness, #babycancer, #childcancer). Hashtags did not appear to be used consistently or in a structured manner and there did not appear to be any existing constructive or coordinated initiative in using childhood cancer related hashtags in a beneficial way to organize knowledge within the childhood cancer community. Nevertheless, the role of hashtags in drawing attention towards childhood cancer-related causes appeared to be fairly popular among the parents recruited for this study.

Table 4. Theme: Raising awareness (Sample Tweets)

Code	Example
Raising awareness about childhood cancer by sharing own child's experience/story	*[user name] please follow/rt.[child] is 4,and has Neuroblastoma cancer.we need to spread awarness of [child's] appeal + this awful cancer xx*
Raising awareness about childhood cancer by sharing tweets from other parents of children living with cancer (or parents of child lost to cancer)	*RT @[other parent]: Today is exactly 6 months since we lost [child] to Neuroblastoma?*

Raising awareness about other disease/illness/cause (not childhood cancer)	*RT @[user name]: OCD Awareness Week - for more information, please visit http://t.co/qFzbLUPb and RT! #ocdweek*
Raising awareness about cause/campaign (not related to a disease or illness)	*RT @chngbereavement: @[parent] My son [child name] died tragically in aug 2010.Pls RT my petition 2 have Bereavement Leave changed <link>*
Requesting not-for-profit/charity organization (not related to childhood cancer) to raise awareness about childhood cancer	*RT @[organization name]: HEY Canadian Mommas! The 2013 @[parent name] Shave 4 the Brave will take place in San Antonio, Texas Want to join?*
Requesting an organization (not directly related to childhood cancer, could be non-profit/charity/business) to raise awareness about childhood cancer	*@DisneyStore please follow/rt.[child name] is 4,loves disney but has Neuroblastoma cancer.please spread the word of her appeal + childhood cancer*
Requesting celebrities to raise awareness about childhood cancer	*RT @[parent user name]: @taylorswift13 please wear a gold ribbon in September Childhood Cancer Awareness Month <link to website>*

Theme 5: Promoting fundraisers and campaigns

Sharing information about fundraising initiatives and campaigns was found to be a major theme among the tweets analysed in our study. Similar to the theme of raising awareness, we found tweets related to promoting fundraisers for childhood cancer related causes, as well as other campaigns that were not directly related to childhood cancer. A majority of the posts that were grouped within this theme were re-tweets, and included a link to an external website (i.e. a Facebook page, website dedicated for fundraising, etc.).

Table 5. Theme: Promoting fundraisers and campaigns (Sample Tweets)

Code	Example
Raising funds for childhood cancer or promoting a childhood cancer related campaign	*RT @ChldhdCancerCan: #GivingTuesday Make a donation to fund #childhoodcancer research by helping our Canadian @[parent user name] reach their goal*
Raising funds or promoting campaigns related to other cause	*RT @[user name]: Power of Play is in 19th place with over 3506 votes in the Aviva Community Fund Contest! Please vote every day! <link>*
Sharing a link for a fundraiser or campaign	*@[user name] Pls RT: 'Wear Festive Red for [child name]' - Fri 14th Dec - our festive fundraising event for [child name]'s Appeal ? <link>*

Theme 6: Being Supportive

The social connection among parents who participated in this study was demonstrated vividly in tweets and re-tweets that relayed updates from each other's children. 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.

We observed that individuals 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. Others shared their happiness and memories to inspire and spread positivity despite the inherent presence of cancer.

Table 6. Theme: Being supportive (Sample tweets)

Code	Example
Retweeting positive updates and news of progress from other children	*RT @[parent]: [child] started chemo on Monday & is doing well. Keep fighting Little Warrior, we are all behind you. Beat #neuroblastoma*
Asking for prayers for child	*RT @[user name]: [child]'s not very well today, getting weaker by the day but she is fighting as hard as she can. Please #prayfor[child].*
Asking for prayers for someone else's child	*Praying for teen #cancer patient in ICU at UNC fighting for his life, and for his fam. #pray4[child] #fb*
Supportive messages for other parents when child is not doing well	*RT @[parent]: Please everyone #prayfor[child] as she goes into the hospice shortly. We need you to #KeepFighting[child] love you so much*
Offering condolences when child passes away	*@[parent] so sorry to hear your news.. you are in our thoughts. xx god bless you all xx*
Sharing quotes about positivity and hope through text and images	*Hope is Powerful: We are beginning to remember ?One year ago? details. <link to blog post from one year ago> #pray4[child]*
Sharing inspirational quotes about working together towards a cure	*"Alone we can do so little; Together we can do so much."~H Keller #MakeSomeNoise 4 kids w/ #cancer*

Theme 7: Talking about personal life and casual conversations

Apart from tweeting about their experience of caring for a child with cancer or sharing information related to childhood cancer, some participants demonstrated a simultaneous lighter side of life. Personal interests, likes and dislikes, as well as individual personalities were present in some of the tweets. Some posts shared humour and funny experiences within the realm of caring for a child with cancer. Others expressed personal opinions on current political events. Religious beliefs also featured fairly frequently within tweets shared by parents of children diagnosed with cancer. Another common phenomenon we observed within the community of parents of children diagnosed with cancer is acknowledging new followers and maintaining frequent interaction with followers on Twitter by responding to tweets posted by other parents of children diagnosed with cancer and answering questions or simple exchanges of daily conversation.

Despite the chaos, anxiety, and uncertainty brought about by childhood cancer that can have drastic effects on a family, participants in our study found time to maintain a sense of normalcy in daily life by sharing bits and pieces of their lives outside cancer.

Table 7. Theme: Talking about personal life and casual conversations (Sample tweets)

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

Discussion

The tweets examined in this study provided glimpses from the stories of families travelling along on a child's journey with cancer. Compared to continuous stories published on blogs (Heilferty, 2009), posts on Twitter allowed larger discontinuities in the storyline and some room for imagination as a consequence of the limitation of a single tweet length. The key themes of tweets revealed in this study suggest that the parents are not only using Twitter to chronicle their child's story of living with cancer, but also to share opinions, feelings, thoughts and perspectives that arise from their and the child's experience. Some of the identified major themes were similar to those found in prior studies. The analysed tweets revealed that parents of children diagnosed with cancer share news articles and links to websites with information related to their particular illness experience. This finding aligns with a study on Alzheimer's patients and family members (Robillard, et al., 2013). Similar to a study on patients diagnosed with esophaegal cancer, this analysis of tweets identified that parents of children diagnosed with cancer are using Twitter as a community to meet each other's informational needs (Chretien et al., 2011; Kaplan, 2012).

In this study, we situated the phenomenon of sharing information through tweets posted by parents of children diagnosed with cancer within the context of Everyday Life Information Seeking (Savolainen, 1995) and information sharing in non-work contexts, as described by Savolainen (2007). Each theme we identified aligned with at least one of Savolainen's motives for information sharing (see Table 8). When aligning themes of tweets to Savolainen's motives, we identified one additional motive for information sharing in the context of online health communication. The additional motive we propose is "endogenous needs", an inherent reason for sharing information due to needs internal or personal to an individual. Of the seven themes identified within the tweets of our participants, five align under the "endogenous needs" motive.

Sharing details about a child's cancer experience may be a means for a parent to manage their own emotions and to feel connected to a supportive community (Chung & Kim, 2007; Rains & Keating, 2011). In that sense, tweets that were grouped under the endogenous needs theme are ones that may not only be beneficial to others looking for families going through a similar experience; these tweets may also be fulfilling an inherently personal need of an individual seeking to connect to a larger community for support. Similarly, tweets grouped within the themes labelled sharing childhood cancer related facts, raising awareness for childhood cancer (or other causes), as well as promoting campaigns and fundraisers could be perceived as being shared for primarily personal reasons inspired by the deeply personal experience of caring for a child 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 considerably. 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 where the tweets posted included topics directly related to childhood cancer as well as unrelated topics of personal interest, and a separate Twitter account dedicated completely to the child's cancer experience. The tweets grouped under the theme labelled personal interests and casual conversations therefore may be aligned with the proposed motive of meeting endogenous needs for information sharing as well.

Savolainen's ELIS framework provides conceptual definitions and categories to situate non-work information practice within boundaries of everyday life. Although the framework is specific for information seeking, in this study we applied the same definitions to contextualize the phenomenon of sharing information through tweets related to a child's cancer experience within

the boundaries of non-work related everyday life information practice. Savolainen (2007) provides examples of non-work contexts as "hobbies, consumer issues, and participation in the activities of civil society" (p. 1). The specific study he used to explore motives of information sharing is based on researching information behaviour of environmental activists. The social context of Savolainen's extensive analysis of everyday life information practice is also largely characteristic of interactions that take place in an in-person face-to-face scenario rather than in online environments such as social media platforms. He discusses the internet in the context of information seeking specifically in analysing the perception of the internet as a source of information (Savolainen, 2008, p. 78), rather than viewing the internet as an all-encompassing social setting for interaction and information sharing among individuals. As such, our study of representing tweets posted by parents of children diagnosed with cancer through the lens of information sharing in an everyday context lends itself to filling a potential gap in Savolainen's motives for non-work related information sharing.

Table 8 shows the alignment of high level themes with Savolainen's three original motives of sharing information, as well as the additional proposed motive. As demonstrated in this table, some of the high level themes were aligned with more than one motive.

Conclusion

Savolainen's Everyday Life Information Seeking (ELIS) framework relates one's way of life with mastery of life in combination with current situational factors and accommodates the process of seeking orienting and problem solving information specific to the problem or challenge at hand (Savolainen, 1995). We used this definition to situate the phenomenon of tweets posted and exchanged by parents of children diagnosed with cancer within the context of Everyday Life

Information Seeking (ELIS) and extended these definitions to associate information sharing (giving and receiving) within everyday life non-work contexts. We focused on the three motives of information sharing in everyday life non-work situations described by Savolainen (2007) and aligned the themes of tweets posted by the parents of children diagnosed with cancer within those motives. We proposed a fourth motive (endogenous needs) for sharing information in an everyday life context, especially for sharing information related to an illness experience within the family as experienced by parents of children diagnosed with cancer. The results from our study therefore add new knowledge and supportive empirical evidence towards explorative studies in the area of everyday life information practice, specifically in the area of parents of children diagnosed with cancer sharing information about their personal experiences online through social media tools.

Table 8. Aligning themes of tweets to motives of information sharing

Serendipitous altruism	Sharing information sought by others	Duty driven sharing	Endogenous needs
Theme 1: Sharing details about child's cancer experience			
	Theme 2: Providing updates about child's treatment	Theme 2: Providing updates about child's treatment	
Theme 3: Sharing childhood cancer related facts			
Theme 4: Raising awareness		Theme 4: Raising awareness	Theme 4: Raising awareness
Theme 5: Promoting campaigns and fundraisers			
Theme 6: Being supportive		Theme 6: Being supportive	
Theme 7: Personal interests and casual conversations			Theme 7: Personal interests and casual conversations

References

American Cancer Society. (2016, January 27). What are the key statistics for childhood cancer? Retrieved from http://www.cancer.org/cancer/cancerinchildren/detailedguide/cancer-in-children-key-statistics

Cancer.Net. (2014, March). Childhood cancer: Overview. Retrieved from http://www.cancer.net/cancer-types/childhood-cancer/overview

Chretien, K. C., Azar, J. & Kind, T. (2011, February 9). Physicians on Twitter. *The Journal of the American Medical Association. 305*(6), 566-568. Chung, D. S.., & Kim, S. (2007). Blogging Activity Among Cancer Patients and Their Companions: Uses, Gratifications, and Predictors of Outcomes. *Journal of the American Society for Information Science and Technology*, *59*(2), 297–306. doi:10.1002/asi.20751

Eichner, J. M. (2003). Family-Centered Care and the Pediatrician's Role. *PEDIATRICS, 112*(3), 691–696. Retrieved from http://www.aappublications.org/

Elkin, N. (2008). *How America Searches: Health and Wellness.* Opinion Research Corporation: iCrossing: 1–17.

Ellis, D. (1989). A Behavioural Model for Information Retrieval System Design. *Journal of Information Science, 15*(4/5), 237–247. doi:10.1177/016555158901500406

Ellison, L., & Janz, T. (2015, November 27). *Childhood cancer incidence and mortality in Canada* (Statistics Canada Catalogue no. 82-624-X) Retrieved from Statistics Canada Website: http://www.statcan.gc.ca/pub/82-624-x/2015001/article/14213-eng.htm

Elo, S., & Kyngäs, H. (2008). The Qualitative Content Analysis Process. *Journal of Advanced Nursing, 62*(1), 107–115. doi:10.1111/j.1365-2648.2007.04569.x

Fernandez-Luque, L., Elahi, N., & Grajales, F. J. (2009). An Analysis of Personal Medical Information Disclosed in YouTube Videos Created by Patients with Multiple Sclerosis. *Studies in Health Technology and Informatics, 150*, 292–296. doi:10.3233/978-1-60750-044-5-292

Hawn, C. (2009). Take Two Aspirin and Tweet Me in the Morning: How Twitter, Facebook, and Other Social Media are Reshaping Health Care. *Health Affairs, 28*(2), 361–368. doi:10.1377/hlthaff.28.2.361

Heilferty, C. M. (2009). Toward a Theory of Online Communication in Illness: Concept Analysis of Illness Blogs. *Journal of Advanced Nursing, 65*(7), 1539–1547. doi:10.1111/j.1365-2648.2009.04996.x

Holm, K. E., Patterson, J. M., & Gurney, J. G. (2003). Parental Involvement and Family-Centered Care in the Diagnostic and Treatment Phases of Childhood Cancer: Results from a Qualitative Study. *Journal of Pediatric Oncology Nursing, 20*(6), 301–313. doi:10.1177/1043454203254984

Horsfall, D., Byrne-Armstrong, H., & Higgs, J. (2001). Researching critical moments. In H. Byrne- Armstrong, J. Higgs, & D. Horsfall (Eds.), *Critical moments in qualitative research* (pp. 3–16). Oxford: Butterworth Heinemann.

Johnson, J. D. (1997). *Cancer-related information seeking*. Cresskill, NJ: Hampton Press.

Kaplan, B. W. (2012). Social Media and Survivorship: Building a Cancer Support Network for the 21st Century. *Oncology nurse advisor, 3*(2), 35. Retrieved from http://www.oncologynurseadvisor.com/

Kuhlthau, C. C. (1993). A Principle of Uncertainty for Information Seeking. *Journal of Documentation*, *49*(4), 339–355. doi:http://dx.doi.org/10.1108/eb026918

Lalonde, C. (2011). *The Twitter Experience: The Role of Twitter in the Formation and Maintenance of Personal Learning Networks* (Unpublished master's thesis). Royal Roads University, Canada. Retrieved from http://dspace.royalroads.ca/docs/handle/10170/451

Lapointe, L., Ramaprasad, J., & Vedel, I. (2014). Creating Health Awareness: a Social Media Enabled Collaboration. *Health and Technology*, *4*(1), 43–57. doi:10.1007/s12553-013-0068-1

Leckie, G. J., Pettigrew, K. E., & Sylvain, C. (1996). Modeling the Information Seeking of Professionals: A General Model Derived from Research on Engineers, Health Care Professionals, and Lawyers. *The Library Quarterly: Information, Community, Policy, 66*(2), 161–193. doi:10.1086/602864

Leininger, M. (1994). Evaluation criteria and critique of qualitative research studies. In J. Morse (Ed.), *Critical issues in qualitative research methods* (pp. 95–115). Thousand Oaks, CA: Sage.

Leydon, G. M., Boulton, M., Moynihan, C., Jones, A., Mossman, J., Boudioni, M., & McPherson, K. (2000). Cancer Patients' Information Needs and Information Seeking Behaviour: in Depth Interview Study. *BMJ: British Medical Journal*, *320*(7239), 909–913. doi:http://dx.doi.org/10.1136/bmj.320.7239.909

Marton, C., & Wei Choo, C. (2012). A Review of Theoretical Models of Health Information Seeking on the Web. *Journal of Documentation*, *68*(3), 330–352. doi:http://dx.doi.org/10.1108/00220411211225575

Moreno, M. A., Egan, K. G., & Brockman, L. (2011). Development of a Researcher Codebook for Use in Evaluating Social Networking Site Profiles. *The Journal of Adolescent Health: Official Publication of the Society for Adolescent Medicine*, *49*(1), 29–35. doi:http://doi.org/10.1016/j.jadohealth.2011.04.015

Patton, M. (2002). *Qualitative research & evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.

Purvis, C. (2012, September 21). Using Twitter to track disease outbreaks. *Security Management*. Retrieved from https://sm.asisonline.org/Pages/using-twitter-track-disease-outbreaks-0010445.aspx

Rains, S. A., & Keating, D. M. (2011). The Social Dimension of Blogging about Health: Health Blogging, Social Support, and Well-Being. *Communication Monographs*, *78*(4), 511–534. doi:10.1080/03637751.2011.618142

Randeree, E. (2009). Exploring Technology Impacts of Healthcare 2.0 Initiatives. *Telemedicine and e-Health, 15*(3), 255–260. doi:10.1089/tmj.2008.0093

Rees, C. E., & Bath, P. A. (2001). Information-Seeking Behaviors of Women with Breast Cancer. Oncology Nursing Forum, 28(5), 899–907.

Rice, P. L., & Ezzy, D. (1999). Qualitative research methods: A health focus. Oxford: Oxford University Press.

Ritterman, J., Osborne, M., & Klein, E. (2009). Using Prediction Markets and Twitter to Predict a Swine Flu Pandemic. 1st International Workshop on Mining Social Media, 9, 9–17.

Robillard, J. M., Johnson, T. W., Hennessey, C., Beattie, B. L., & Illes, J. (2013). Aging 2.0: Health Information about Dementia on Twitter. *PLoS ONE, 8*(7), 1–5. doi:10.1371/journal.pone.0069861

Sandelowski, M. (2002). Reembodying Qualitative Enquiry. *Qualitative Health Research*, *12*(1), 104–115.

Sarasohn-Kahn, J. (2008). *The Wisdom of Patients: Health Care Meets Online Social Media.* Retrieved from California Health Care Foundation: http://www.chcf.org/~/media/MEDIA%20LIBRARY%20Files/PDF/PDF%20H/PDF%20HealthCareSocialMedia.pdf

Savolainen, R. (1995). Everyday Life Information Seeking: Approaching Information Seeking in the Context of "Way of Life". *Library & Information Science Research, 17*(3), 259–294. doi:10.1016/0740-8188(95)90048-9

Savolainen, R. (2007). Motives for Giving Information in Non-Work Contexts and the Expectations of Reciprocity. The Case of Environmental Activists. *Proceedings of the American Society for Information Science and Technology, 44*(1), 1-13. doi:10.1002/meet.1450440210

Savolainen, R. (2008). *Everyday information practices: a Social phenomenological perspective*. Lanham, MD: Scarecrow Press.

Schutz, A. (1967). *The phenomenology of the social world.* (G. Walsh & F. Lehnert, Trans.). Evanston, IL: North Western University Press.

Thompson, M. A. (2014). Social media in clinical trials. In D. S. Dizon (Ed.), *American Society of Clinical Oncology Educational Book.* doi:10.14694/EdBook_AM.2014.34.e101.

Tobin, G., & Begley, C. (2004). Methodological Rigour within a Qualitative Framework. *Journal of Advanced Nursing*, *48*(4), 388–396. doi:10.111/j.1365-2648.2004.03207.x

Twitter. (2016). About. Retrieved from https://about.twitter.com/company

Wiener, L., Crum, C., Grady, C., & Merchant, M. (2012). To Friend or Not to Friend: The Use of Social Media in Clinical Oncology. *Journal of Oncology Practice*, 8(2), 103–106. doi:10.1200/JOP.2011.000357

Wilson, T. D. (1999). Exploring Models of Information Behaviour: the "Uncertainty" Project." *Journal Information Processing and Management: an International Journal- Special issue on Information Seeking in Context* (ISIC), *35*(6), 839–849. doi:10.1016/S0306-4573(99)00029-1

Ziebland, S., & Wyke, S. (2012). Health and Illness in a Connected World: How Might Sharing Experiences on the Internet Affect People's Health? *Milbank Quarterly, 90*(2), 219–249. doi:10.1111/j.1468-0009.2012.00662.x