

Personalizing Healthcare Online: Experiences of Care Providers and Families who 'Blog'

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Abstract

Communication and social technologies (Internet, social media, and mobile devices) are impacting traditional healthcare communication and care practices, demonstrating that care providers need to learn how to adapt to a new 21st century healthcare landscape. This research presents a unique perspective about how one healthcare organization has successfully adopted the use of a blog as an extension to its clinical care services. Using ethnographic content analysis (ECA), I analyze Boston Children's Hospital's *Thriving* blog to interpret users' emotions, experiences, and behaviours. Findings reveal substantial two-way user engagement and three overarching emotional/social themes, highlighting the effectiveness of *Thriving* as a welcoming virtual space for individuals to publicly voice their triumphs, sorrows, and journeys toward healing while benefiting from engagement with others in a supportive online community. Findings from this study may be important for healthcare organizations looking to understand how to implement similar online engagement tools.

Keywords: healthcare communication, communication/social technologies, blog, ethnographic content analysis (ECA), participatory medicine

Over the past decade, society has experienced a significant shift in how people communicate due to the emergence of communication and social technologies such as the Internet, social media, and mobile devices. These changes have become increasingly prominent in the healthcare sector. As the use and evolution of technology becomes more influential in people's lives, the healthcare sector is experiencing widespread and unfamiliar changes in traditional communication and care practices with patients, families, and the general public. This research study investigates how one healthcare organization has adopted the use of a blog for its stakeholders. Overall, there exists little empirical research into the perceived benefits of blogging in healthcare, especially in terms of users' overall experiences, and if blogging further enhances the quality of care provided by healthcare organizations. My research demonstrates that individuals who receive healthcare services may benefit from blogging by 'voicing' their personal stories, receiving words of encouragement, and making meaningful connections in a supportive online community. Likewise, healthcare organizations and medical personnel may also benefit by building relationships with stakeholders, incorporating a personal touch to their online presence, and spreading information about treatment services and research initiatives.

Research shows that 69% of adults in the USA and 70% of Canadians use the Internet for health-related activities such as searching for health information or tracking health issues (Pew Internet & American Life Project, 2013; Statistics Canada, 2012). These statistics suggest that people are exploring health-related topics online, demonstrating an overall increased interest in personal health awareness, and potentially educating themselves and becoming more actively involved in self-care management. Additionally, the huge popularity of mobile technology is putting health-related information into the hands of patients (and potentially family or friends) at the "precise moment health decisions are being made" (Hesse et al., 2011, p. 19). As a result of

these changes, traditional healthcare is undergoing rapid and potentially long-lasting change, which suggests that technology may actually represent a golden opportunity for the healthcare sector to envision how it will evolve in the 21st century and more effectively meet the needs of the people it serves (Nathenson, 2010).

My personal background in healthcare for the past 15 years is the inspiration for my research. In recent years, I have witnessed how these new technologies foster uncertainty and anxiety for many in the healthcare sector due, in large part, to a lack of understanding of their potential benefits. Without doubt, technology will continue to influence healthcare communication and care practices, and I therefore wish to develop my understanding for how patient/provider engagement can be enhanced through the adoption of these new communication tools. Using ethnographic content analysis (ECA), a technique for analyzing online content, I explore how a blog is a viable communication tool for healthcare organizations, engaging their patients, their families, and its staff. When I began looking for healthcare organizations using blogs I found about a dozen, but I was immediately drawn to Boston Children's *Thriving* due to its distinct features such as the appealing layout and design, extensive use of personal photographs, and links to additional information. But, more importantly, the uniqueness and authenticity of the stories shared by families and care providers ultimately led me on this quest to explore *Thriving* more deeply.

With this research, I aim to provide valuable insight to those in healthcare who hope to foster a more rounded, patient-focused care experience in light of emerging communication and social technologies. By incorporating these tools, the healthcare sector may be better equipped to meet the needs of patients and their families in our increasingly technology-driven culture.

Literature Review

As the evolution and use of communication and social technologies influences society-at-large, its impacts and potential benefits for the healthcare sector are a significant area of study (Boyer, 2011; Broom, 2005; Gianchandani, 2011; Hawn, 2009; Kim & Kim, 2009; Lober & Flowers, 2011). In fact, Broom (2005) suggests that healthcare is in the midst of a “revolution” as tools such as the Internet and social media are becoming increasingly prominent sources of information for the general public (p. 325). There is literature which reflects the view that healthcare systems may benefit from learning how to optimize technology to educate the public about disease, provide support for those who need it, and reduce healthcare costs. Gianchandani (2011), for example, argues that technology has the potential to make “tomorrow’s health-care system more safe, effective, reliable, and timely” (p. 121). Based on this view, traditional healthcare communication and care processes may evolve in the future through the integration of tools such as the Internet and social media into these specialized environments.

Prior to the emergence of new technologies, traditional doctor-patient interactions were “top-down and somewhat paternalistic” as patients would listen carefully to what their doctor said and do exactly what he prescribed to get better (Lupton, 1994, p. 56). Since the arrival of the Internet, recent studies have investigated the impact of this technology on patient/physician relationships and the patient’s overall experience. A study conducted by Kim & Kim (2009), for example, found that physicians felt patients’ use of the Internet was becoming increasingly influential during their conversations, suggesting that the Internet is changing the dynamics of these unique and personal relationships. Using an interpretive research approach, Broom (2005) also examined patient/physician interactions to understand the attitudes of physicians who dealt with “Internet-informed” patients (p. 325). Findings from this study showed that physicians felt

that the Internet had contributed positively to their interactions and patients' overall feeling of empowerment because they felt more knowledgeable about their symptoms or disease.

Additionally, this study showed that physicians felt the use of the Internet in general would ultimately lead to safer and better patient care. These studies suggest that, while technology is certainly posing some challenges to traditional doctor/patient dialogue, it may also lead to enhanced communication and understanding between care providers and patients.

Other studies have examined the increasing trends of consumer empowerment due to the influx of 21st century communication and social technologies and how this phenomenon is impacting the healthcare sector. Lober & Flowers (2011), for example, argue that recent trends in overall consumer empowerment are beneficial to the healthcare sector because people are becoming increasingly consumed by the ease and accessibility of technology, which may have a great deal to offer healthcare as a tool for improved patient/provider engagement. While it is generally accepted that there are clear distinctions between 'consumers' and 'patients', particularly in Canada, this notion highlights the significance of *service delivery* in healthcare environments. Similarly, Gianchandani (2011) suggests that further research about how technology can facilitate "transformation in care delivery" is needed so that everyone involved in healthcare processes can work more effectively together as a way to sustain healthcare systems in the future (p. 121). This view is shared by the *Society for Participatory Medicine*, which launched in 2009 to advocate for healthcare systems that support patients and caregivers building partnerships through tools such as the Internet and social media.

Recent studies have explored the huge appeal of social media as a ubiquitous tool through which personal dialogue can be shared, and how this technology is becoming increasingly prevalent in some healthcare contexts. Compared with other sectors, healthcare has been

relatively slow to embrace social media and experiment with integrating these tools into healthcare environments, yet patients and their families in need of emotional/social support are readily turning to this technology. Lober & Flowers (2011) argue that social media allows patients to “engage with the broader social milieu and...bring their chosen ‘milieu’ with them,” which is particularly important for those dealing with complex or troubling health issues (p. 177). *PatientsLikeMe*, for example, was founded in 2004 as an online support network where patients can voice their personal health journeys for the benefit of healing themselves and connecting with others who share similar health issues. Such online platforms have been evolving since the early 2000’s, allowing patients to share their thoughts and pose questions, providing them with a sense of comfort by knowing they are not alone in dealing with their disease. The Mayo Clinic in the United States of America is considered a leader in using social media to enhance their existing healthcare services since it started its own Facebook page in 2008. In 2012, they published *Bringing the Social Media Revolution to Health Care* to educate care providers with how to effectively integrate these two-way communication tools into healthcare contexts.

While research into blogging in healthcare is limited, there are studies that demonstrate an increasing use of blogs in healthcare contexts. In particular, research shows that specific medical fields are experimenting with blogging to facilitate improved communication and build relationships with their patients. Walden (2012), for example, examined the behaviors of 17 naturopathic physician bloggers and found that the opportunity to start a dialogue with patients, answer patients’ questions, build trust, and increase public awareness about naturopathic medicine were all key drivers for blogging practices (pp 5-8). Similarly, Adams (2010) conducted two case studies on the use of healthcare-related blogs in the Netherlands. She was

interested in “health goal-oriented” blogging and what aspects of blogs were deemed most important to individuals using this technology (p. e89). Interestingly, her findings showed that, while blogging certainly provides an open platform for online discussions about a variety of topics, further research is needed about user experiences to gain more understanding into what benefits, if any, exist with the use of blogs in healthcare contexts (p. e93). She suggested that such analysis is necessary “to make any detailed claims about blogging for health from the patient perspective,” which would lead to greater understanding about how to use blog technology to improve healthcare communication, patient experiences, and care services (p. e93).

Finally, with new technologies becoming an increasingly predominant force in the healthcare sector, the concept of *participatory medicine* has emerged as a potential catalyst toward a more cooperative healthcare system; a model of care that fosters provider/patient engagement, patient empowerment, and education through the exchange of information and improved communication strategies with tools such as the Internet and social media (Society for Participatory Medicine). With such a model, a more sustainable healthcare system could potentially be realized in the future, not only supported by greater efficiency, but also by better communication between patients and care providers. In 2005, terms such as “ePatients”, “eHealth”, and “Health/Medicine 2.0” began emerging to further our understanding of how technologies are influencing traditional healthcare processes (Hesse et al., 2011). ePatient Dave, for example, is considered the first patient to take an active role in his cancer treatment by using the Internet and a personal blog to share his experiences online and learn from others undergoing similar treatments. He recently published *Let Patients Help!* as a guide for healthcare providers and patients to collaborate with each other more effectively through the optimization of

technology (epatientdave.com). Metzger & Flanagin (2011) further highlight this notion of “experiential credibility” to describe how people who have direct experience with a particular disease, treatment, or therapy “gain credence given the unique features of digitally networked media” (p. 49). These studies suggest that a more participative approach to healthcare may be beneficial in the future and, with healthcare becoming more complex and demands for services increasing, digital technologies may be a practical, low-cost addition to existing healthcare services (Fordis et al, 2011).

From this research, it seems clear that recent advances in communication and social technologies pose challenges to traditional healthcare communication and care processes. The healthcare sector must therefore find novel ways to meet the needs of patients and their families in the 21st century, which may be possible through the adoption of these sophisticated tools. The Internet and social media have much to offer healthcare, particularly as cost effective tools to enhance patient/provider engagement, build relationships with stakeholders, and circulate health-related information to a vast and varied audience. While adaptation on the part of care providers is challenging, it is necessary if the healthcare sector is to evolve in the wake of the digital revolution. This study builds upon previous research by focusing specifically on how Boston Children’s Hospital has successfully implemented the use of a blog for patients, their families, its staff, and the general public.

Methods

This research is adapted from Altheide and Schneider (2013). Ethnographic content analysis (ECA) provided the underlying research framework to analyze texts, visuals, and auditory elements from the data sample. ECA is a qualitative research technique to explore media ‘documents’ by extracting meanings and developing themes in an emergent way. With

this method, researchers will obtain a greater understanding of the cultural aspects, symbolic meanings, and social behaviors as represented in the area of study (Altheide & Schneider, 2013, p. 107).

Thriving is Boston Children's Hospital's pediatric health blog and the site of analysis for this research. The blog is a hybrid of online social activity with narratives, images, and videos, each requiring thorough analysis of the meanings that emerge from these elements to further our understanding about how *Thriving* may benefit its users. With this in mind, the central question of this study is: How does *Thriving* benefit the sick children and families who seek treatment at Boston Children's Hospital, and their care providers, and what is the significance of this for the healthcare sector? Additional questions guiding this research and data collection include: (1) what are the characteristics of *Thriving* that support the notion of *participatory medicine*; (2) who are the primary users and audience of *Thriving*; and (3) in what ways does *Thriving* reflect the culture of Boston Children's Hospital? In addition to the blog under study, sites of analysis include scholarly peer reviewed journals, books, textbooks, and white papers.

At the onset of data collection, purposive sampling was used to select a small number of blog posts for initial analysis (Altheide & Schneider, 2013). During this phase, several dozen posts written over a two-year period were analyzed to become familiar with *Thriving*, including its authors, types of stories, and visual layout/design. Early on, three specific themes became apparent – *hope* for the future, expressions of *love*, and feelings of *courage* during difficult life challenges – which were evident in several *Thriving* blog posts. Theoretical sampling was therefore applied to select twelve blogs posts that elicited, in either an exemplary or unique fashion, these three overarching themes (p. 56). In qualitative media analysis, the selection of a small sample set is most ideal for in-depth exploration, resulting in much richer and more

meaningful findings and, in addition, closer examination of the similarities and differences between the units of analysis (Altheide & Schneider, 2013). The twelve posts include stories written by staff of Boston Children's Hospital and guest bloggers. The data set was downloaded to Word files on February 24, 2013, examined by following a protocol specific to this study (see Appendix), and later saved as PDF documents. Protocols allow a researcher to assign categories/coding, analyze discourse, and ask relevant questions while guiding data collection, giving the researcher the opportunity to study each post systematically and capture emergent themes and significant features (p. 44).

As with all ethnographic studies, a researcher's personal engagement with the area of study is crucial for themes and meanings to emerge. Through *hope*, *love*, and *courage*, the three overarching themes in the data sample, I reflected on how bloggers represented their experiences and, more interestingly, acted on their emotions. Sample posts were chosen based on their uniqueness and ability to elicit emotion in me and potentially other readers or 'lurkers' on *Thriving*. Each *Thriving* story is a sincere offering of self-expression, engaging readers deeply into the personal/public lives of bloggers. Additionally, while qualitative analysis was the overarching research method for this study, quantitative techniques were applied to analyze the relevance of comments, Facebook likes, and Tweets, for example. The following analysis represents my personal impressions of the stories as not only a researcher, but also as a member of the public with free access to *Thriving*.

Results

Overall, *Thriving* is a welcoming public/private virtual space for families of sick children, their care providers, and the general public to express their personal feelings, opinions, and experiences. The twelve posts of the data set address several different health issues from various

emotional/social perspectives. Indeed, the stories provide information about Boston Children's treatment services and specific health topics but, more importantly, the narratives personalize the experiences of families and caregivers by allowing these individuals to 'voice' their personal health journeys and experiences of healing. The posts are authentic and real in that bloggers' use of language is reflective and very descriptive about themselves and their personal life challenges. Bloggers write about children who have fought to overcome life-threatening medical conditions, their visions of brighter futures for their family, and the deep pain and sorrow they felt (and continue to feel) after the loss of a child. Bloggers share their personal perspectives in detail and how, through care treatment at Boston Children's, they can now look toward positive change in their lives. Families, for example, express their heartfelt appreciation to the hospital saying, "we will be forever grateful to the people at Boston Children's" and "[we] are very grateful our son will have the chance to travel the long road to recovery." Statements from Boston Children's staff are equally self-expressive such as "I feel very proud to be part of the Children's team" and "everything went according to plan thanks to the amazing efforts of the whole team," presenting *Thriving* readers with a positive image of the healthcare services, culture, and teamwork at Boston Children's. As well, audience and family/patient engagement is facilitated through *Thriving* as bloggers experience reciprocal words of encouragement and support. A common statement throughout blog *comments*, for example, is "thank you for sharing your story," and "wishing you and your family the very best," highlighting the unique two-way communication features of blog platforms. During data analysis of the twelve sample posts, three salient themes emerged – *hope* for the future, expressions of *love*, and feelings of *courage* during difficult life challenges – which are described ethnographically throughout the remainder of this section.

Hope for the Future

By remaining hopeful that one day their child may no longer suffer, *Thriving* families write narratives about how they personally cope with the challenge of having a very sick child. One touching story of hope is beautifully expressed in *Hope for children with a rare “aging” disease*. Accompanying the story is a video introducing *Thriving’s* audience to a young girl named Megan who lives with an extremely rare disease called progeria, a condition which causes young children to age severely and rapidly, often dying by the age of 13. Viewers see Megan as an extremely thin little girl with no hair and wrinkled, pale skin. She has the physical features of an old woman rather than those of a child and she is one of 28 children from 16 countries (75% of all known progeria cases worldwide) to have entered the first ever clinical trial to find a cure for progeria. Megan’s mom and dad describe their experiences saying,

We’ve always had hope from the beginning that things will turn out well. Now that they’ve told us certain things are looking better, it’s just what we’ve wanted the whole time. We had nothing three years ago. It feels like we won the lottery.

The video is a rare opportunity to see how these children interact with their families and Boston Children’s staff. A young boy and girl are also seen in the video, each with similar physical features to Megan, looking intently at their doctor and listening carefully to her every word. Dr. Kieran, Director, Pediatric Medical Neuro-Oncology, describes the initial results of the clinical trial saying,

We saw a significant increase in their ability to gain weight and significant changes in their cardiovascular system. The understanding that we gain from children with progeria may be important, not just for families of children with progeria, but for the larger population.

There is a light-hearted photo of Megan, smiling at her virtual audience as she hugs her stuffed kangaroo. The story is a fascinating example of patient/family/provider engagement, giving the audience a positive impression of the innovative care at Boston Children's.

Feelings of hope are similarly shared by Alexis' mother in *A is for Alexis* as she says "we all saw Alexis not as a collection of wrongness, but as a bundle of hope." She describes at length how Alexis' 15 health challenges continually define how people see her daughter, but that she only sees hope in her and what is 'right' because "A not only stands for Alexis, it stands for awesome." She writes that families of children with multiple health issues often hear considerable negative dialogue from care providers and that a more positive, open, and friendly approach would alleviate some of their anxieties. She says, "as a parent of a sick child, I'm asking medical professionals to think about how their actions impact those they treat, outside of tests and prescriptions." A collection of color photographs of Alexis and her family allow *Thriving* readers to see and connect with Alexis and her family, adding to the effectiveness and impact of their message to readers and Boston Children's staff.

Stories of hope from families are mirrored by Boston Children's medical personnel who also frequently express how hope drives them in their work. An excerpt from one physician in *From boos to hope: Challenging the dogma about deadly brain stem gliomas*, demonstrates one medical team's feelings of hope perfectly. He says,

For the first time, we should be able to give children with DIPG (diffuse intrinsic pontine glioma) like Hailey personalized treatment options based on the makeup of their individual tumor. We have the opportunity to look within DIPG and understand why it differs so greatly from other tumors, which will help us map out better strategies for the future.

The narrative tells the story about six-year-old Hailey who is the first patient to participate in a clinical trial that has been 40 years in the making because, up until now, surgical techniques to safely remove these rare tumors were not available. The initiative, one physician says, “brings the hope that, in the future, more children will be able to survive this largely mysterious tumor.” A photograph of Hailey shows her looking fatigued but relaxed, sitting on an examining table with her doctors smiling beside her. The photograph is particularly effective at adding a real life element to the story, giving *Thriving* readers a visual representation of the doctor/patient dynamics at the hospital and demonstrating meaningful engagement/partnerships with patients.

Expressions of *Love*

Expressions of love were overwhelming throughout the sample posts, not only from parents toward their child, but also from Boston Children’s staff toward their young patients and families. Some bloggers (and audience members) use the word “love” saying, “we love you Ari, love you Children’s Hospital Team!!!,” while others were obviously moved based on the notion of love. One of the most poignant examples of love is shared in *Celebrating the ones that slipped away*, a post written by Meaghan who is a registered nurse at Boston Children’s. She describes the deep sadness she felt, and continues to feel, after the loss of her patient, Ava. She says,

Almost every nurse and physician who works at Children’s Hospital Boston has experienced a growing attachment to and love for a patient that they ultimately had to say good-bye to. In some cases that patient becomes part of who you are, both as a healthcare provider and a person. Ava is my patient that got away.

Meaghan’s language is noticeably sincere. She expresses her feelings on the day staff and families come together to remember children who passed away the previous year at Boston

Children's annual *Time to Remember Ceremony*. Along with the heartfelt personal narrative, there is a photo of baby Ava with several tubes going in and out of her tiny body, sleeping with stuffed animals and cards surrounding her. Another photo of Ava's mom and dad shows them holding Ava's hands and smiling warmly at their virtual audience. The photos add a personal touch to Meaghan's story that extends beyond the personal narrative.

Love and sorrow are similarly shared by Dr. Claire McCarthy, a frequent *Thriving* blogger, who shares her personal story in *Being the mother of a child who died—on Mother's Day*. She reflects on the death of her own child and how her experiences continue to define who she is as not only a parent, but also as a healthcare provider. She says,

At first, we are different because of our raw sadness. But over time, the sadness moves from our skin into our bones. It becomes less visible, but no less who we are. It changes into a wisdom, one we'd give up in a heartbeat to have our child back. We who have lost children understand life's fragility and beauty. We who have lost children understand that so many things just aren't important. All that is important is those we love. All that is important is each other. Nothing else.

Dr. McCarthy's narrative is sincere, honest, and deeply personal and likely connects her more closely with her audience (and quite likely her patients and their families) by representing herself as an approachable, sympathetic, and understanding medical professional.

These sample posts differ dramatically from those sharing love with *Thriving* audiences in happier contexts. Holidays, for example, are celebrated at Boston Children's and Halloween is one such holiday that the staff clearly enjoy as a loving gesture toward their young patients. In *Halloween—Boston Children's style*, one staff member says, "we provide costumes for all the kids and teens and setup trick-or-treat stations at all the nurse stations." The accompanying video

shows Halloween ‘in action’ with babies, young children, teens, and adults dressed in a variety of costumes while staff sing and play the ukulele in the hospital corridor.

Another positive and heart-warming expression of love is written by Alexis’ mom who says,

After years of treatment and following Alexis through one challenging diagnosis after another, one of Alexis’s doctors recently watched her walk out of her sixth annual checkup, hand-in-hand with her dad. The pediatrician was so moved by all Alexis has overcome she started to cry. She told me later that the tears started flowing because she was so proud of Alexis, so proud of us as parents and proud of herself and her staff for helping everyone get this far.

These stories indicate that bloggers use *Thriving* as a way to release some of their deeply rooted feelings, allowing them to heal and find solace through self-expression.

Feelings of *Courage* during Difficult Life Challenges

Though the particular stories vary considerably, several sample posts reflect on the level of courage needed by families and care providers as they face difficult medical and/or life challenges. *Dominic’s craniofacial surgery*, for example, is a remarkable story about a baby boy named Dominic who was born with two extremely rare and severe facial abnormalities. Several photos show Dominic with a golf ball-sized growth in the middle of his face that splits his nose and mouth in two and forces his eyes wide apart. The narrative describes how Dominic’s abnormality, combined with his underlying health condition, is so rare that he was not expected to survive birth let alone be strong enough to withstand hours of extensive reconstruction to his face. His father says,

At first we were told he would probably die within a few hours and that we should do our best to enjoy the pregnancy [but] over time his prognosis got better, and the doctors agreed he'd survive birth. But after that, they had no idea what may happen to him.

The post is long and descriptive as Dominic's parents and Boston Children's staff tell the story about how Dominic continued to thrive despite his condition. The medical team describes what would take weeks of planning for his upcoming surgery, which ultimately involved 15 people and lasted for several hours. An excerpt written by Dr. John Meara, plastic surgeon in-chief, demonstrates how his team faced the challenge of treating Dominic. He says,

To correct a condition as complex as Dominic's takes a lot of work, from many very talented people, an operation like this can be dangerous and lengthy. If you don't have the right team it could take up to 12 to 18 hours but I knew with the right preparation we could work more efficiently, posing less risk to the patient.

The final image of baby Dominic shows one faint scar from the top of his head down his nose and another from his right ear to the top of his head; he is smiling brightly and the growth in the middle of his face is gone. This story likely shapes *Thriving* readers' impressions of the Boston Children's medical team, their level of expertise, and the exceptional services of the hospital for families who have children with unique medical situations.

Another courageous story is shared by a father in *Children's in the News: courageous Children's family speaks with Boston Globe*. He describes his family's remarkable transition with the support of Boston Children's Gender Management Services (GeMS) clinic, explaining how he and his wife have collaborated closely with the hospital for several years to support their son throughout his gender transition. The GeMS clinic continues to support the family and today

Nicole and her twin brother Jonas are teenagers. Their photos on *Thriving* show only their back-side but a link to their story in the Boston Globe takes readers to an up-close picture of the teens' faces, looking purposefully and warmly at their virtual audience. Their father says,

Until recently we chose to remain anonymous [but] since our kids have recently entered their teens, we felt it would be more damaging for them to not have a voice and stay hidden away. We are still scared of the unknown and still fearful of the extreme misunderstanding that exists around transgender issues. But by sharing our story we hope that others might better understand, accept and support transgender children.

In this case, Nicole and Jonas' family use *Thriving* to openly share their personal opinions, give their children a voice, and speak out publicly about an often misunderstood condition.

In *Mock my pants, not my sister*, *Thriving* audiences learn about Dr. Brian Skotko, a physician at Boston Children's Down Syndrome Program and the older brother of a girl with Down Syndrome. He makes a similar public plea to *Thriving* readers, speaking out against a recent article that attributes Boston's poor fashion sense to "a kind of style Down Syndrome, where a little extra ends up ruining everything." He says,

If my friends who are black were mocked, they would not take it. If my friends who are gay were slurred, they would not take it. My 400,000 fellow Americans with Down syndrome have been cheapened, and I will not take it.

Dr. Skotko's strong language serves as a powerful and effective message to *Thriving* readers that people with mental/physical challenges should be treated with respect and dignity. A spirited image of Dr. Skotko and his sister, Kristin, shows him wearing hot pink pants, a paisley tie, and a checkered shirt as they both smile from ear to ear.

This collection of examples of *hope*, *love*, and *courage* demonstrate the benefits of *Thriving* as a tool for emotional/social self-expression by families and care providers at Boston Children's hospital. Evidently, the site gives bloggers a virtual space where private human sentiment can be openly shared, allowing those who suffer from significant health challenges the opportunity to find solace and express their innermost feelings while benefitting from reciprocal expressions of heartfelt sympathy and support. From these examples, it seems clear that *Thriving* is a sophisticated non-traditional communication platform (for a hospital setting), giving users empowerment by participating in a "mature online community" with members who continuously strive to support each other's needs (Bernoff & Li, 2012, p. 151). This interaction likely leads to stronger connections among Boston Children's patients, families, and care providers and is a practical way through which the personnel can present themselves as approachable, highly skilled, and sympathetic to their patient's needs.

Audience Engagement through *Thriving*

One of the most interesting features of the sample posts was the high level of audience engagement through comments, Tweets, and Facebook likes (Table 1). *Mock my pants not my sister*, for example, generated a huge volume of comments (263) and Facebook likes (24,000), suggesting that this story was shared with hundreds (or potentially thousands) of people in any number of online networks. Bernoff & Li (2012) suggest that the "desire to connect, to create, to stay in touch, and to help each other are universal," and demonstrated in this study of *Thriving* through the quantity and quality of audience engagement. Comments frequently contain words of encouragement and support for bloggers. In *Courageous Children's family speaks with Boston Globe*, for example, one commenter says,

Thank you for sharing your family's story with the rest of us. I'm a young trans woman who recently stepped forward publicly with my story as well and I want Nicole to know that there is love, real love is out there for her. I used to worry about finding love as a teen in transition as well, and eventually found the love of my life in adulthood. I'm here to let her know that it's possible.

Another comment says, "I don't know you or your family but reading this piece touched my heart" and similarly,

Thank you so much for this story Dr. McCarthy. My son died in Children's Hospital Boston 21 years ago. It still hurts, but you are so correct. It is not on the skin anymore it is in my bones. I love and miss him so much.

Table 1

Social Media Metrics Per Blog Post

Post	Title	Date	Words	Photos/Images	Videos	Links	Comments	Tweets	Facebook likes	LinkedIn shares
1	Our patient's stories: A is for Alexis	20-Aug-12	860	4	-	2	9	12	89	24
2	Children's in the News: Courageous Children's family speaks with Boston Globe	12-Dec-11	666	2	-	4	5	23	342	2
3	Our patient's stories: Mickey's got heart	19-Dec-12	945	4	-	4*	4	8	178	0
4	The heart of innovation	14-Feb-12	720	4	-	5*	0	8	229	5
5	Our patient's stories: Dominic's craniofacial surgery	28-Jan-13	1,262	6	-	6	24	22	971	14
6	Taking the world by storm: keeping up with Ari Schultz	02-Jul-12	1,540	5	-	5	42	8	295	25
7	Mock my pants, not my sister	18-Jul-12	408	1	-	4*	263	584	24,000	56
8	Being the mother of a child who died-on Mother's Day	15-May-12	740	1	-	2	9	3	132	3
9	From boos to hope: Challenging the dogma about deadly brain stell gliomas	21-May-12	829	3	-	8*	6	8	351	1
10	Celebrating the ones that slipped away	25-May-11	531	3	-	1	7	6	179	1
11	Halloween - Boston Children's style	02-Nov-12	143	2	1	1*	0	11	178	4
12	Hope for children with a rare "aging" disease	25-Sep-12	277	1	1	6	1	3	51	0
*	Contains 1 or more broken links									

These comments suggest that *Thriving* users may be taking advantage of the site to give/receive support from others, further highlighting how blogging can lead to meaningful online engagement. Moreover, it was evident that bloggers made connections outside of *Thriving*, demonstrating that the site may be particularly promising for families to share their experiential knowledge and develop relationships with any number of families looking for answers related to their health questions. For example, in *Challenging the dogma about deadly brain stem gliomas*, one commenter says,

My nephew was just diagnosed with dpig. I wish there was some way to get in touch with someone in this trial. My sister is trying to make a decision and it is so difficult without support. He is already symptomatic and time is of the essence here. Please reply here. It looks like I can't leave my contact information, but anyone please help. And Hailey's mother responds, saying, "please email me." Such comments illustrate how *Thriving* stories may be extending to other support networks reflective of particular diseases or experiences.

Another feature of the sample set that adds significantly to audience engagement and, more importantly, readers' ability to experience *Thriving* stories are the multimedia features such as *images* (36) and *videos* (2). All stories contain at least one visual, which are typically photos of the child and his/her parents during their treatment at Boston Children's. The photos are real and expressive, giving the audience a chance to personally connect with the children and their families by seeing who they are. There are also photos of Boston Children's staff alongside patients and/or families, which are very effective at showcasing real-life doctor/patient dynamics at the hospital. *Halloween – Boston Children's style* and *Hope for children with rare "aging" disease* also include videos,

which provide living images of the story and the opportunity to hear their voices, giving readers a truly ‘real-life’ experience. *Links* also connect *Thriving* readers to additional information on the Boston Children’s website such as specialized programs, disease descriptions, and physician’s personal web pages, encouraging readers to explore the site more deeply. Some posts also provide links to additional news articles specific to the *Thriving* story such as the Boston Globe, Huffington Post, and the Boston Herald and links to information about related clinical trials. Finally, *Thriving* stories are diverse and frequent with new posts added at least weekly. The layout/design asks users to “share your story” and “post a comment,” encouraging the continuation of audience engagement.

Discussion

This study reports results from an ethnographic content analysis (ECA) of *Thriving* – a pediatric health blog hosted and managed by Boston Children’s Hospital. While blogging in healthcare organizations is a relatively new concept, it is gaining popularity as a viable communication medium for patients, their families or friends, healthcare providers, and others seeking support or information related to their personal situation. Findings from this research support the adoption of blogs in healthcare contexts as a feasible ‘shift’ from the traditional, top-down approach of healthcare communication and care services to more open, two-way, and participatory engagement among everyone involved with managing acute or chronic illness. Overall, *Thriving* provides an effective online support mechanism for parents of sick children and Boston Children’s staff to voice their experiences and benefit from building connections in an online environment. In particular, the honesty and authenticity of the human sentiments shared on *Thriving* provide the necessary foundation for open/transparent engagement to occur in this online space. Abrams and Lefebvre (2009) suggest that individuals’ use of blogs represents

“an important increase in the power of self-expression by the public,” giving *Thriving* users the opportunity to exercise their right for self-expression (p. 419). Bloggers express themselves through transparent and deeply personal narratives as a way to heal their own deeply embedded wounds and to support others experiencing similar health and emotional challenges. Parents and Boston Children’s staff demonstrate their comfort level by freely pouring out their feelings on *Thriving*, suggesting that online emotional/social support mechanisms can be extremely meaningful to those facing difficult health challenges. Moreover, *Thriving* bloggers are open to sharing their stories through photos (and videos in two cases) and do not shy away from putting themselves on ‘display’ in front of others. Miller, Pole & Batemen (2011) argue that healthcare blogs “have the potential to foster support networks among bloggers and readers sharing similar experiences,” which this study of *Thriving* notably demonstrates (p. 742). Metzger & Flanagin (2012) further equate this “architecture of participation” to a network of like-minded people who wish to share their knowledge and make substantive virtual connections with others in the community, which is clearly evident on *Thriving* through the exchange of comments, Tweets, Facebook ‘likes’, and LinkedIn shares (p. 50). Finally, because *Thriving* is a public site, it serves as a practical, low-cost mechanism for Boston Children’s Hospital to spread valuable health-related information with a wide audience.

Limitations

This study had some limitations. First, the parameters of this research excluded the specific use of human subjects through surveys and/or interviews, for example. I did not speak directly with patients, families, or physicians to retrieve more in depth data concerning their impressions and responses to *Thriving*, participatory medicine, or blogging in general. Second, data analysis was exclusively based on my interpretation of the interactive dynamics occurring

exclusively online. However, my interpretations of *Thriving* could be applied to analyze blogs hosted by other healthcare organizations. Third, this study excluded the impressions of families and care providers who have access to *Thriving* but are resistant to using it or those who lack access to or knowledge of digital technology in general. Fourth, the content on *Thriving* would be difficult to comprehend, if not impossible, for someone with limited ability to read as the language is best understood by textually advanced readers. However, the underlying meanings and messages represented in photos and videos could be understood by those with limited or no reading ability. Finally, while sample posts were saved to Word and PDF documents, I frequently referred to the ‘live’ posts to validate links, re-watch videos, and ensure all content was captured. In qualitative media analysis the continued study of live documents is necessary, which can be problematic if, for example, the website is ‘down’ or other technical difficulties present barriers to investigation.

Conclusion and Closing Remarks

Communication and social technologies (Internet, social media, and mobile devices) have become fundamental components of our society and, as such, their use and popularity in healthcare is expected to grow. In fact, according to Hesse et al. (2011), technology “may be supplementing – or even replacing – the in-office professional consultation of previous years” (p. 24). Healthcare providers must therefore position themselves to integrate these tools into their everyday communication processes and care services if they hope to meet the needs of the people they serve in the foreseeable future. One strategy is through the adoption of a blog. This study of *Thriving* is evidence that the two-way, communicative features of blogs are highly beneficial in healthcare contexts. Specifically, *Thriving* is an ideal example of a participatory healthcare model with actively engaged users who take advantage of its unique two-way

communication features to give and receive emotional/social support, foster meaningful online connections, and build engagement. Abrams & Lefebvre (2009) highlight the huge potential of online communication, suggesting that “small acts of engagement – especially in a social network context – may have...rippling effects throughout a social network” (p. 420). The hosts of *Thriving* therefore have an advantage by tapping into the *blogosphere* to further their understanding of how patients, their families, and staff use the site for emotional/social self-expression – nurturing their well-being and sharing valuable health-related information across the network and potentially beyond (Bernoff & Li, 2013, p. 19).

Moving away from one-on-one patient/physician interactions and taking advantage of one-to-many online support networks will further enhance the healthcare sector’s ability to partner with their stakeholders, enabling a collaborative healthcare model that gives those with health challenges a ‘tool’ whereby they can support each other. Online communities, like *Thriving*, are built around improving the quality of life for their members with actively engaged participants who have a strong desire to share their knowledge for the benefit the community-at-large (p. 19). This “collective intelligence” can be further exploited by ‘listening’ to the conversations taking place on *Thriving* and applying that information to tailor Boston Children’s Hospital’s care services to more effectively meet the needs of their patients, families, and caregivers (Hesse et al., 2011). At the same time, it is important to regularly monitor blog activity to ensure invalid or potentially misleading information is not spreading amongst the group.

Future research must seek to explore blog user experiences by conducting interviews and/or surveys with those using such technology and those who choose not to. Questions to be addressed should include willingness to openly participate, suggestions for site design/layout, and privacy/confidentiality concerns. Future studies about blogging practices will further our

understanding of how to effectively use this technology in healthcare contexts to enhance patient/provider engagement and build partnerships among all stakeholders. Building on this research will ultimately assist healthcare organizations with how to develop a system that fosters participation, communication, and active engagement, improving healthcare systems in the future and more effectively meeting the needs of patients, families, and healthcare providers.

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Appendix

“Thriving” Data Collection Protocol

Date of posting

Title of posting

Author

Words

Number of:

- Comments
- Reactions
- Tweets
- FaceBook Likes
- LinkedIn shares
- Other

Tags

File format: Saved as Word document later converted to PDF

Topic/focus of Posting (e.g. unconditional love, medical miracle)

Search terms/key words (e.g. human feelings/expressions of emotions):

- Hope
- Love
- Courage
- Strength
- Help
- Support
- Inspiration/inspire
- Miracles
- Loss/sadness/sorrow
- Other

Frame (e.g. Childhood cancer)

Themes: (e.g. hope, love, courage)

Primary Data: text, links to other webpages on Boston Children’s website, other)

Other data (e.g. images, videos, comments)

- Photo/video caption
- Topic/focus of artefact
- Size and/or length
- Scene

Language: narrative and story-telling of personal experiences/life lessons/self-expression/sharing with others

Perspective/view

Researcher’s notes (reflexive summary of posting and/or AV content)

Poignant quotation(s)