The devil you know: parental online information seeking after a paediatric cancer diagnosis

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Abstract

There is a growing interest in understanding the effect that online information seeking has on patient experiences, empowerment, and interactions with health care providers. This mixed-methods study combines surveys and in-depth interviews with 41 parents of paediatric cancer patients in the US to examine how parents think about, evaluate, access, and use the Internet to seek information related to their child's cancer. We find that during the acute crisis of a child being diagnosed with cancer parents preferred to receive information related to their child's diagnosis, prognosis, and treatment options from a trusted health care provider rather than through the Internet. To this end, we find that access to medically related cancer information through the Internet was deemed untrustworthy and frightening. Parents' reasons for avoiding online information seeking included fear of what they might find out, uncertainty about the accuracy of information online, being overloaded by the volume of information online, and having been told not to go online by oncologists. Some parents also had logistical barriers to accessing the Internet. While most parents did not turn to the Internet as a source of health-related information, many did use the Internet to connect with sources of social support throughout their child's illness.

Introduction

In recent decades scholars have argued that there has been a socio-cultural shift in health care encounters, marked by shifting patient/provider roles, increased patient consumerism, and direct patient access to medical and health related information through the Internet (Casper and Morrison 2010; Timmermans and Oh 2010; Boyer and Lutfey 2010). Within this body of research on the changing relationship between patients and health care providers, scholars place large emphasis on the central role of online information seeking (Casper and Morrison 2010; Timmermans and Oh 2010; Boyer and Lutfey 2010). Many argue that the widespread access and use of the Internet provides patients with quick, unfettered access to a broad range of health related information and support, and this access largely contributed to the shift from physician-as-expert to patient-as-consumer health care encounters.

With the emergence of the Internet, direct to patient marketing, and the social construct of the patient-as-consumer, the concept of the empowered patient has become an important framework for understanding shifting patient roles when interacting with health care. Within the empowered patient construct, patients are encouraged to be self-advocates and participate as equals in medical decision making (Salmon and Hall 2004). The Internet is often interwoven in discussions of patient empowerment, as it is seen as one of the primary vehicles through which patients can empower themselves with information, confidence, and support to bring to their health care encounters. Research has documented the important role of the Internet in enhancing patient self-advocacy in routine health care encounters and when confronting rare or contested illnesses (Gundersen 2010; Schaffer et al. 2008; Barker 2008). However, we do not yet have a complete understanding of how the Internet is used during times of potentially life threatening and acute illness. In this paper, we draw from surveys and in-depth interviews with parents of paediatric cancer patients to better understand how parents of seriously ill children think about, evaluate, access, and use the Internet to seek information related to their child's cancer. In doing this, we seek to understand how parents of critically ill children perceive the Internet as a health-related resource, and the effect of this on their encounters with health care providers.

Background

Evolving patient and physician roles

Scholars have articulated a shift in patient and physician roles in the US that occurred during the late twentieth century (Timmermans and Oh 2010). As the for-profit heath care industry grew in the US, changing incentive structures shifted the patient-provider encounter. With this change in the structure of the health care bureaucracy in the late twentieth century, research has shown a decline in patients' trust in their physicians (Lipset and Scheneider 1982; Pescosolido et al. 2001; Timmermans and Oh 2010; Boyer and Lutfey 2010), as well as the evolution of the patient-as-consumer (Timmermans and Oh 2010; Boyer and Lutfey 2010). With this decline of patients' trust in their physicians, a growing socio-cultural emphasis emerged encouraging patients to advocate for themselves in health care encounters. This has been marked by increased consumerist attitudes of patients and challenges to the expert role of physicians (Stacey et al. 2009; Boyer and Lutfey 2010). Research shows that relationships between patients and physicians have become less hierarchical, and more client-provider oriented (Timmermans and Oh 2010; Boyer and Lutfey 2010). At the same time, there are extensive cultural messages surrounding the need for patients to take an active role in their own health care, be an advocate for themselves, and participate in health care decisions (Stacey et al 2009). This focus on the empowered patient is also fuelled by the increased information available to patients, largely through the Internet (Boyer and Lutfey 2010).

The role of the Internet in the medical encounter

Patient use of the Internet has been a focus of scholarship in sociology, medicine, and health services research (Timmermans and Oh 2010; Boyer and Lutfey 2010; Casper and Morrison 2010; Ziebland 2004). This body of research has examined patients' use of the Internet to access health related information (Seçkin 2010; Czaja et al. 2003; Rutten et al. 2006), gain confidence in the health context (Ybarra and Suman 2006; Hay et al. 2008) and gain a sense of control over their own health (Rains 2007). Sociologists have been particularly interested in understanding the role the Internet plays in eliminating boundaries between patients and health information, and the subsequent effect this has on patients' sense of empowerment over their health and health care interactions (Casper and Morrison 2010; Boyer and Lutfey 2010; Timmermans and Oh 2010; Henwood et al. 2003; Kivits 2009; Hardey 1999; Ziebland 2004; Kivits 2004).

As access to the Internet has become increasingly common in homes, workplaces, hospitals, and educational institutions, researchers have sought to understand how individuals use this resource in relation to their own health. The Internet presents unfiltered access to a broad range of health-related information from varied sources, perspectives, and levels of endorsement from the health complex. Access to resources on the Internet provides patients with direct sources of information that has not been filtered by their health care provider. It also has the potential to provide resources and information to bolster patients' abilities to question their physician's opinion, seek alternate treatment options, and access second opinions.

Despite this, we do not have a complete understanding of how patients use the Internet across a range of health care experiences, and how this use is interwoven with broader health care interactions. Some research points to the Internet as a tool in patients gaining a sense of empowerment over their health care, and documents patients using the Internet to connect with alternate courses of therapy. Scholars argue that this enhanced access to health related information is a catalyst in the reconstitution of the lay-professional boundaries in medicine and subsequent patient empowerment (Ball and Lillis, 2001; Hardey 1999, 2001, 2002; Stacey et al. 2009; Ziebland 2004; Loader et al 2002). Others contend that the role of the Internet in patient empowerment is context dependent, and constrained by patients' demographic and social backgrounds, attitudes toward self-advocacy, and propensity to seek medical information online (Hirji 2004; Henwood et al. 2003; Salmon and Hall 2004). This body of research points to a more complicated story of the Internet's role in patient empowerment. While previous research has revealed that the Internet is a powerful resource for patients facing rare or contested illnesses (Gundersen 2010; Schaffer et al. 2008; Barker 2008), we do not have a complete understanding of patients' actual levels of use of the Internet as a source of health information in times of serious illness, and how this affects patient/provider relationships (Ziebland 2004).

The Case: Families Battling Paediatric Cancer

Most of the parents in this study took their child to their doctor because of fairly routine seeming symptoms: fatigue, complaints of pain, or feeling like they had the flu. For many, their child's cancer diagnosis was a complete shock, and began a whirlwind of hospital visits, doctors' appointments, and immersion into the health care community. Paediatric cancer serves as an interesting case to examine the use of the Internet both due to the severity of the diagnosis, and the typical course of treatment. While the initial diagnosis necessitates a series of quick, high stakes decisions, treatment typically extends over months and sometimes years. Throughout this time, there are commonly key decision-making opportunities that parents are involved in as their child responds, or does not respond as hoped, to initial therapy. There are also countless hospital-based, charity, not-for-profit, and parent initiated websites offering information and resources related to paediatric cancer. For these reasons, paediatric cancer serves as an appropriate case through which to examine how parents of seriously ill children use the Internet.

Methods

Data Collection

The data come from a larger study on families' health care navigation after a paediatric cancer diagnosis. The first phase of the study was ethnographic, and followed five families of paediatric cancer patients over a six-month period, and is reported in more detail in earlier manuscripts (Gage 2010). The second phase of the study was mixed-methods, and involved both a survey and structured in-depth interview component. The analyses for this paper are based upon the interview and survey data from the second phase of the study.

Respondents were recruited through two hospital-based paediatric oncology clinics in the same Northeastern city of the US. The paediatric psychologists and social workers approached families and introduced the study. With the families' consent, the social workers forwarded their contact information to the study team, and an interviewer contacted each family. Since we were recruiting families directly through paediatric oncology units, the families in this study all had children who were actively undergoing intensive cancer treatment. These families interacted with multiple clinical teams throughout their child's cancer care, including paediatric, surgical, radiation, and medical oncologists. The study team waited at least four weeks after an initial diagnosis to approach families. Due to the circumstances of the study, a precise response rate is difficult to calculate. We had no refusals when families were initially approached; however, the volatile nature of their child's condition made participation emotionally or logistically burdensome for several families who initially agreed, but later indefinitely postponed or declined participation.

A sociologist led the study team, and an advanced sociology doctoral student conducted all interviews with white respondents. An African American researcher in one hospital's Office of Health Disparities conducted interviews with eleven of the African American respondents. Due to scheduling difficulties, two of the African American respondents were interviewed by the white interviewer. All researchers were from an academic setting, with no clinical experience. During the informed consent process respondents were assured that their responses would not be shared with any members of their child's health care team, that the study was not connected to their child's care in any way, and that the research team was not associated with their child's health care team. Interviewers met respondents at their homes, in the hospital while their children were inpatient, and at coffee shops. The study was IRB approved, and respondents signed a written informed consent. Respondents were first asked to complete a survey that consisted of demographic questions adapted from the MacArthur Foundation Research Network on Socioeconomic Status and Health Socio-demographic questionnaire (Singh-Manoux et al. 2003; Singh-Manoux et al. 2005). An in-depth structured interview was then conducted that focused on how parents discovered their child's cancer, information seeking, decision making, interacting with clinicians, parenting, finances and work experiences. Each participant was offered a $50 gift card to thank them for their participation.

Data Analysis

Each interview was transcribed verbatim and added to interviewer's observation notes. Demographic information from the survey was added to each respondent data file, including race, gender, marital status, household income, subjective social status, wealth, occupation and education. Two members of the research team carefully read and coded interview data. Coding meetings were held where both members of the team brought their coded data and each transcript was discussed. Inter-coder reliability was established at coding meetings, discrepancies were resolved, and consensus among coders was established. Data analysis was guided by the principles of grounded theory. Forty-four codes were developed based on the interview guide, interviewers' field experiences, a review of the literature, and themes that emerged from the data. The qualitative analysis software NVivo8 was used to assist with data analysis. Themes were identified based upon the relationship between codes and the frequency of codes. New codes and themes emerged throughout the period of data analysis, and data were continuously re-examined.

Sample Characteristics

The sample consists of 41 respondents (table 1). 26 were women and 15 were men. 68% of the sample was white, and 66% married. The largest proportion of respondents had a high school diploma (54%) and 27% had a total household income of $100,000 or greater.

Results

They said it would scare us if we went online

When discussing how they accessed information about their child's cancer, an overarching theme in our data was that respondents did not conduct significant medically related Internet research after their child's diagnosis. Parents were fearful and untrusting of the kinds of information they might find on cancer-related websites. Respondents also described feeling more comfortable receiving information about their child's prognosis and treatment options from a source that they deemed trustworthy – most commonly an oncologist. The most common reason parents provided for not seeking information online was because their child's oncologists told them not to. This was a theme among parents whose children were treated by different health care teams and oncologists at both hospitals. In addition to this, parents expressed fear at what they might find out, being overwhelmed by the information on the Internet, and questioning the reliability of information available on the Internet.

When asked if they went online to seek information about their child's cancer, parents described being instructed not to go online in their initial conversations with clinicians after their child's cancer diagnosis. This was the most common theme among respondents' reasons for not using the Internet throughout their child's cancer care. One mother explains,

> In the very beginning [the oncologist] said 'don't go on the Internet because it's going to scare you and confuse you.' So we just never do it. We just totally stay away from it as far as cancer goes. The only [research we have conducted is] from the information that they have given us and that we have got from the Leukaemia Society. [Respondent #28, female, married, high school diploma]

Like this mother, other respondents indicated that their child's oncologist had specifically told them not to conduct Internet research on their child's cancer, fearing that this information would scare them. Parents commonly cited this as their primary reason for not engaging in online information seeking after their child's diagnosis. Similar to the mother quoted above, many parents described feeling comfortable relying on the information provided by their child's health care team, and preferred this method of receiving information about their child's cancer over information found online. This mother's sentiment of actively avoiding certain kinds of cancer-related information on the Internet was another consistent theme among respondents. In this way, parents described being afraid of encountering certain types of information on cancer-related websites, and preferred to receive information related to their child's cancer diagnosis, prognosis, and treatment from a trusted health care professional.

Fear of what they might find out should they conduct their own Internet research was a theme among respondents. Another parent explains,

> They told us not to research [patient-male]'s cancer… because it's so rare. They said it would scare us if we went online because it's such a rare cancer, they didn't really know anything about it. They told us not to so we didn't. [Respondent #15, female, divorced, bachelor's degree]

Some parents described relying on supplemental materials provided by the hospital or clinicians, as a way to avoid sifting through information on the Internet on their own. Oncologists also warned parents about misinformation on the Internet, and parents often expressed this as their reason for not seeking information about their child's cancer online.

> **Interviewer:** After your daughter was diagnosed, how did you get information about possible treatment options?
>
> **Respondent 18:** [The oncologist]

Interviewer: Did you ever do any research on your own?

Respondent 18: Uh, no not really because one of the first things that [the oncologist] mentions to you is that by going out on the Internet, there's no control over the information you're actually reading. It's very difficult to tell if you're actually reading something that's pertinent or let's say, less than reliable. [Respondent #18, male, married, bachelor's degree]

When asked about seeking information on the Internet, parents repeatedly used language of fear and trust. Respondents feared what they might find out if they went online, and placed trust in the information provided by the oncologists, hospital, and other sources they deemed to be legitimate (such as the Leukaemia/Lymphoma Society, and direct connections with experts). In this way, they preferred to have a trusted health care professional mediate the cancer-related medical information they received, and trusted these professionals' judgement in determining what information parents should receive.

Fear, Uncertainty, and Overload

Respondents cited fear as a primary reason for not seeking information on the Internet. Some described having conversations with their child's oncologist about becoming unnecessarily scared by unfiltered information on the Internet. Others described their own fear of what they might find out if they went online. One mother explains,

I was afraid to go online because I figured if I needed any questions answered, I would just ask the staff at [the hospital]… What I did was I went downstairs, [the hospital] has a resource room. They have all types of booklets, pamphlets and I just grabbed everything that they had on leukaemia and I just started reading. But that was the information that I went through because I was afraid to go online it's not very accurate and the doctors made us aware of that. [Respondent #17, female, married, bachelor's degree]

Like other parents, this mother preferred to educate herself through hospital library materials rather than through the Internet. While this mother was seeking additional information about her child's cancer, she avoided using the Internet as a resource due to her fears of inaccuracy of online information and warnings from her child's doctors.

Parents also expressed fear of the unknown as a reason for putting their trust in their child's physicians, and allowing them to filter the information they received about their child's cancer. Another parent explains,

I don't like to read a lot about other people's horror stories. It's just you hear enough [at the hospital] it's scary enough. I've tried to just follow what our doctors say and stick with that. [Respondent #21, female, married, master's degree]

Fear of what they might find out if they went online was a common theme throughout respondents' beliefs about the Internet. Parents described being more comfortable hearing medically related information regarding their child's cancer care directly from health care professionals than taking the risk of encountering "horror stories" on the Internet.

Parents also feared not being able to cope with information they might receive online. One mother describes avoiding the Internet as a way to maintain hope throughout her son's cancer care,

Respondent 11: My family carried the BRCA gene for [breast] cancer and when my cousin was diagnosed and when my aunt was diagnosed, I was the person that was the keeper of all the information. I did extensive research. I can't with this. I

can't. I can't look at anything that's going to take me down a different path than what I believe is going to happen.

Interviewer: Has anyone else in your family done any type of research?

Respondent 11: If they have, they have not told me. (Laughs) [Respondent #11, female, married, bachelor's degree]

As this mother describes, she did not want to burden herself with worries about worst-case scenarios. Putting their trust in the physicians and not seeking information online was an active coping strategy for many respondents.

In addition to this, parents described being overwhelmed by the information on the Internet, and learning to avoid seeking information online as they navigated their child's cancer care. One parent explains,

> I made the mistake of hitting the Internet shortly after he was diagnosed and I stopped doing that. The information can be brutal…The news can be utterly devastating. The stuff I found immediately after he was diagnosed, he was borderline stage 3. So doctors were saying he was days within going into full blast. None of the drugs at that point were effective at the blast stage. The mortality rate was very high. So I stopped doing that. [Respondent #3, male, married, bachelor's degree]

Like this father, other respondents echoed sentiments of learning early on to avoid searching for information on the Internet. Respondents also questioned the reliability of information available on the Internet, and cited this as a reason for not seeking information online. One respondent describes,

> [The doctors] advised us against doing much [Internet research] because not everything that's on the Internet is true. It's not filtered for truth. It's not filtered for people with wild attitudes…Going to the Internet, you don't have a filtering system to know what's right and what's wrong. [Respondent #27, male, married, associate degree]

Many parents discussed feeling more comfortable allowing their child's oncologists to be their gatekeepers to cancer related information. One parent describes,

> We [went online] at first and we try to stay away from it now. We just — it was one of those, we weren't too sure how reliable the information was on the Internet. Some of the resources are very helpful but others are also just kind of scary. We tried to stay with reputable [websites] like leukaemia/lymphoma society websites and medical websites that we could verify. Now we find that we can get the best information just by talking to the staff at [the hospital]. [Respondent #4, female, married, bachelor's degree]

Like this mother, respondents preferred to get their information from "reputable" sources, or directly from the hospital resources, rather than sifting through potentially inaccurate information online. Another mother describes actively trying to avoid information from the Internet because of her conviction that it is unreliable,

> I really got into an argument with my friend because she said 'you're an educated woman. You need to get on the Internet and start reading.' Other people were like 'I read this or I saw this.' Finally I was like 'you need to stop. First of all it's not your child, it's my child. Secondly, it's the Internet.' Are you kidding me? I would drive myself crazy with reading everything that there is out there. I have pushed all of that stuff away because I believe [his doctors are] the experts. I choose not to [go

online] because there are so many diverse opinions out there. There's so much garbage out there. [Respondent #21, female, married, master's degree]

As this mother illustrates, parents described avoiding the Internet as a way of protecting themselves from becoming more scared about their child's prognosis, overwhelmed, and prey to unreliable information related to paediatric cancer. In this way, parents viewed many cancer-related websites not as a source of information, but as something they actively tried to insulate themselves from.

Logistical Barriers to Internet Use

Other parents discussed a lack of technology literacy as a reason they did not go online to seek additional information after their child's cancer diagnosis. One parent responded, "Truth be told, I didn't even know that stuff like that existed online." [Respondent #5, female, single, associate's degree] Another mother explained, "I'm not one to be on the computer a lot. I'm not a big computer fan (laughs). I only do what I have to and then get off." [Respondent #6, female, married, associate's degree]

When asked whether they sought additional information, some respondents described the speed at which decisions were made after their child's diagnosis. They cited this whirlwind as a reason for not using the Internet to seek additional information about their child's diagnosis and treatment options. One parent describes,

> Basically we just went with what they told, what the hospital [told us]… It was so fast; they were just kind of like 'This is what happens.' So we kind of stuck with what the doctors said. [Respondent #12, female, married, bachelor's degree]

Parents also discussed the extreme disruption to their normal routine, and simply not having time to seek information online. These logistical difficulties constrained their ability to spend time seeking additional information on the Internet. One parent explains "[I went online] a little but, not a whole lot. I really didn't have time to do a whole lot." [Respondent #19, female, single, high school degree]

Uses for the Internet: Clarifying, Defining, and Connecting

While respondents echoed themes of fear and being tentative about extensive online information seeking, they also found certain kinds of information seeking on the Internet helpful. Parents described going online to seek basic medical information related to their child's care. This most commonly included defining medical terms, clarifying information physicians had given them, and getting additional information on treatment options. Most of these parents described their child's oncologist as being their primary source of information, and using the Internet to clarify discussions they had with clinicians. One mother describes using the Internet to supplement information provided by her child's physicians,

> **Respondent 6:** [We got our information through] the hospital. The hospital did it all. We trusted them. They got her through the first time. Trusted them completely [when she relapsed].
>
> **Interviewer:** Did you ever do research on the Internet?
>
> **Respondent 6:** With the bone marrow transplant, when they tried to explain it to us but you know, you can only take it so much so I personally did searches trying to get a little more information exactly how the transplant works and all that stuff. Even — the first time she had cancer though, it took a while to fathom it anyways but I can't say I went in and did research on it but [after she relapsed] I did because it was too different…I would search the specific cancer and go from there. With the transplant, I just searched bone marrow transplant and stuff like that just to narrow

> it. I wasn't going to check everything. I just wanted to get specifics. [Respondent #6, female, married, associate's degree]

Other parents echoed this mother's experience of using the Internet to help define terms and enhance their understanding of their child's cancer. One parent explains, "I think the only time I really looked at anything was right after he was diagnosed. I think I looked up what leukaemia was because I really didn't understand exactly what it was. I think that's the only time I did that." [Respondent #13, male, married, master's degree] Another father explains how he used the Internet, "[I searched] What is leukaemia? How does it work? What are these things that they're giving him? That kind of stuff. What are the protocols? Those kind of things. What does this word mean?" [Respondent #27, male, married, associate's degree] These respondents described the Internet as a useful tool in gaining basic knowledge about their child's cancer and cancer therapy. They described doing searches through general Internet search engines such as Google, or using WebMD to define terms and clarify treatment protocols.

Social Support and Social Networking

While respondents in our sample did not engage in extensive online medical information seeking, parents did describe using the Internet to connect with other types of resources to bring to their battle with paediatric cancer. This included communicating with friends and family and connecting with new sources of support. A theme among respondents was difficulty communicating updates on their child's condition with friends and family members. Parents used the Internet as a way to remove the emotional burden of constantly talking about their child's illness. One father explains,

> We did get into CaringBridge so family members can go online and see how he's doing. My wife [maintains our site]. Before we go in [to the hospital], after we come back, she lets people know how things are going. When the surgery is going to be…There's been a lot of people going on there. Family members from out of state or other counties that aren't close to us that they can just stop on and see him. [Respondent #23, male, married, high school degree]

Parents also used the Internet and other technology to mediate social relationships throughout their child's illness, and remove the emotional burden of disseminating information. Another mother describes,

> Mostly, like even during the surgery I was getting texts and texting back. I mean, it's hard to always talk on the phone, especially in front of [my daughter]; you've got to watch what you say. One of my oldest daughter's friends made a website, you know a Facebook "We All Love [Sarah]" and we put a lot of stuff on there of her progress and how she was doing. In the meantime she got her own little Facebook [page] and basically that's where everybody keeps an eye on her. We kind of let the other site go. I don't have my own Facebook [page] and I'm not one to think that it's the greatest thing, but I know there are other sites you can do, like CaringBridge and things like that, but you know what? It worked for us and that's where people, they tell me they check Facebook to see what [Sarah]'s up to or what's next or whatever. [Respondent #40, female, married, bachelor's degree]

Internet sites dedicated to tracking a patient's cancer journey were helpful vehicles in quickly disseminating updates related to a child's cancer care for many families. Respondents described these being most helpful during the most intensive parts of their child's treatment, and removed the emotional and logistical burden of providing constant updates to friends and family. As this mother describes, maintaining these Internet sites also provided an opportunity for family and friends to provide support to the cancer patient and their family.

Another theme among respondents was finding social support through connections made online. One father describes how online connections have been helpful in connecting his family with additional support and information,

> [My daughter] has a website to deal with her disease and [my wife] updates it constantly…she'll talk to other moms. She'll communicate with other moms because sometimes other moms have got on and talked to her on [our daughter]'s CaringBridge site… that's how [my wife] learned a lot of stuff just being there and talking to other [parents]. [Respondent #9, male, married, high school degree]

Some families found web-based social networking sites helpful ways to connect with other families who have experienced paediatric cancer, and engage with their own extended networks of friends and family. In this way, the Internet served as a useful facilitator, which connected families with resources and sources of support. However, similarly to their experiences with medical information seeking online, parents balanced the benefits of these Internet sites against a fear of possible negative experiences. One respondent describes,

> They're blogs. You go on there and you update how the family member or even yourself are doing with cancer. You just hop on it. You can Google any of them. I couldn't tell you off hand what ones I have gone on but you go on and they're actually pretty cool. You have to use the references on them because if you go on one and it's got terrible people on there. You just want to stay away from them. Anything with a .org is pretty cool but if it's a .com, it's not a real good idea. They got some pretty mean, nasty people out there. [Respondent #16, female, married, high school degree]

Similar to parents' fear of the information they might find when seeking medical information on the Internet, parents echoed feelings of fear and apprehension when using the Internet to connect with other families who were dealing with cancer. In this way, discussions of the potential utility of the Internet were often balanced with cautions of being careful when going online.

Discussion

A primary focus of medical sociology has been to grapple with the changing relationship between patients and health care providers. Recently, scholars have emphasized the role of the Internet as a catalyst in this socio-cultural shift to patients-as-consumers. This study builds upon the discussion regarding the role of the Internet in shifting the historically hierarchical dynamics between patients and health care providers, and finds that in the case of serious paediatric illness parents did not heavily rely on the Internet to connect with health information related to their child's care. We find that during the acute crisis of a child being diagnosed with cancer, parents preferred to receive information related to their child's diagnosis, prognosis, and treatment options from a trusted health care provider rather than through the Internet. To this end, we find that access to certain kinds of medically related cancer information through the Internet was deemed untrustworthy and frightening, while parents preferred to have health-related information mediated by health care providers whom they had established relationships with.

We find that parents of paediatric cancer patients fear encountering certain types of information – stories of other families' tragedies, inaccurate medical information, conflicting opinions – on cancer related websites. This fear was bolstered by several factors, including advice from their child's oncologist, uncertainty, and overload. Parents preferred to receive medically related information regarding their child's cancer directly from a trusted source, most commonly a health care provider. When they did engage in information seeking beyond their child's primary health care team, parents sought sources they deemed

"legitimate" such as materials from the hospital library, direct research in medical journals, and from other health care professionals directly.

Findings also suggest that there may be an important theoretical distinction between online information seeking for routine and chronic conditions versus serious and potentially life-threatening health problems. Respondents' repeated emphasis of fear of cancer-related information on the Internet suggests that the type of health issue being confronted may be a critical dimension in understanding how, when, and why patients use the Internet as a source of health information. It may be that individuals prefer to equip themselves with additional information to bring to their routine health care interactions, but in times of acute health crisis the fear of the unknown outweighs some individuals' desire to seek information online. Future research should focus on comparing types of health information being sought, as a way to further explore this potential contextual effect on online information seeking versus non-seeking. It may be that some people are not simply online information seekers, or non-seekers, but that these behaviours are highly context dependent and an individual may seek information online for some health-related experiences, and not others.

In light of the widespread socio-cultural emphasis on patient empowerment, we find that in the case of the acute crisis of paediatric cancer, parents describe being overwhelmed, untrusting, and scared of what they may find out if they seek medically related information on the Internet. It may be that during the highly emotional and chaotic period immediately following a child's cancer diagnosis parents did not want to be 'empowered' though the Internet but instead wanted to place their child's care in the hands of a trusted professional. Amid an onslaught of fast-paced, high-stakes decisions parents may want to transfer some of the burden of decision making to a health care professional rather than taking on the additional emotional and logistical burden of sifting through medical information on the Internet. Previous scholars have identified patients' desire to have physicians remove some of the burden of decision making in health care encounters (Ingelfinger 1980). Henwood and colleagues (2003) extend this critique of patient empowerment, and find that women in their sample who were seeking care for menopausal symptoms preferred to leave decisions to their physicians and not seek health-related information on their own. Our findings build upon these findings, revealing that these parents of paediatric cancer patients did not seek additional health related information on the Internet, and preferred to receive information related to their child's care form a "trusted" source, most commonly an oncologist.

Interestingly, a striking proportion of parents' explanations of why they did not seek information online was because their child's oncologist warned them not to. It is possible that this reasoning is a response to the increased pressure on patients to be 'empowered' self-advocates. Parents may be citing their oncologist's recommendation to avoid the Internet as a way to credibly deflect social pressure to avail themselves of every possible resource in advocating for their children. In the same way that parents prefer to receive information related to their child's treatment and prognosis from a trusted intermediary, they may also be transferring the burden of defying a societal expectation to be an empowered patient to their child's oncologist. In this way, their rationalization that a trusted expert advised them to avoid the Internet allows them to credibly respond to societal pressure to seek additional information on the Internet.

This study fills an important gap in the literature by examining how parents use the Internet in times of serious paediatric illness. However, some data limitations should be taken into account when interpreting these findings. First, all respondents in the sample were parents of paediatric cancer patients. As such, their experiences may be particular to the experience of paediatric cancer. Also, while the qualitative data offers a rich and nuanced view of the experiences of these particular respondents, the small sample size means that these findings

should be regarded as suggestive rather than broadly generalizable. Still, the analysis sheds important insight into use of the Internet after a serious medical diagnosis. Future research should examine these processes in larger samples of patients facing a broad range of illnesses.

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Table 1

Demographic Characteristics of Sample

	Percentage of Total Sample N in Parenthesis
Gender	
Women	63% (26)
Men	37% (15)
Total	100% (41)
Race/Ethnicity	
Non-Hispanic White	68% (28)
Non-Hispanic Black	32% (13)
Total	100% (41)
Marital Status	
Never Married	29% (12)
Married	66% (27)
Divorced	5% (2)
Total	100% (41)
Education	
Less than high school diploma	5% (2)
High school diploma or equivalency (GED)	57% (23)
Associate degree (junior college)	7% (3)
Bachelor's degree	15% (6)
Master's degree	10% (4)
No Response	7% (3)
Total	100% (41)
Total Household Income	
Less than $5,000	10% (4)
$5,000 through $11,999	12% (5)
$12,000 through $15,999	5% (2)
$16,000 through $24,999	5% (2)
$25,000 through $34,999	2% (1)
$35,000 through $49,999	7% (3)
$50,000 through $74,999	20% (8)
$75,000 through $99,999	5% (2)
$100,000 and greater	27% (11)
Don't Know/No Response	7% (3)
Total	100% (41)