

Phoenix Children's Hospital

Understanding Parents' Health Information Needs When Their Child is Newly Diagnosed with Cancer

Recommendation Report

Tessa Audet
April 2017

Executive Summary

The purpose of this report is to offer Phoenix Children's Hospital (PCH) recommendations for improvements to their website in order to provide parents whose child has been newly diagnosed with cancer the most clear and appropriate health information. I conducted a study in order to analyze and evaluate the health information content currently provided to parents at PCH. This was done by through qualitative coding methods on both printed documents provided by The Emily Center Library, as well as interviews conducted with three Hematology/Oncology nurses at PCH. Additionally, I researched the current literature surrounding this topic in order to provide a background of information. Based on the results, I recommended that PCH offer parents a comprehensive cancer database in which all provided information would be searchable via their website. This database would also allow them to expand on their two topic focuses: home care and emotional support. Additionally, I recommended that parents are provided information on how to identify credible and non-credible sources on the Internet so that they can find information that is truly medically valuable when searching for information on their own. Lastly, I offered future recommendations that will require continued research so that PCH's provided health information can continue to grow and improve.

Table of Contents

Introduction...3

Background Research: A Review of the Literature...3

Health Literacy...3

Information Needs of Caregivers of Children Diagnosed with Cancer...4

Methods...5

Documents...6

Interviews...6

Coding...7

Results...7

Documents...7

Frequent Codes...7

Table 1...8

Medical Category...8

Figure 1...9

Figure 2...9

Emotions Category...10

Figure 3...10

Other Codes...10

Interviews...11

Frequent Codes...11

Table 2...11

Discussion...11

Background Research...12

Emotional Support...12

Online Information Seeking...13

Journey Board Application...15

Phoenix Children's Overall Focus...15

Phoenix Children's Website...16

Recommendations...16

Table 3...17

Cancer Database...17

Figure 4...18

Figure 5...19

Source Credibility...20

Future Recommendations...20

Conclusion...21

References...23

Appendix A...24

Appendix B...26

Introduction

Parents with a child newly diagnosed with cancer are going through an extreme emotional trauma. It is essential for hospitals, like Phoenix Children's Hospital (PCH), to provide their families the necessary information so that they can both better care for their sick child and make informed decisions about the child's health. This study was designed in order to analyze and evaluate the health information content currently provided to parents at PCH. Additionally, nursing staff was interviewed in order to obtain greater insight into the needs of these parents. I analyzed on both the health information as well as the interviews through qualitative coding methods. As the Internet can play a large role in health information seeking, this study focuses on what content PCH can add specifically to their website in order to meet the needs of parents whose child has been diagnosed with cancer. This is important to understand so that hospitals, like PCH, can provide the appropriate content, via their trusted website, to parents during a very difficult and overwhelming time.

Background Research: A Review of the Literature

I conducted research on the current literature surrounding this topic in order to provide a basis of information for this study. This section looks at the term *health literacy* and how it might impact one's online health information seeking. Additionally, similar studies that looked at the needs of caregivers and parents of children with cancer are included and provide a foundation in which the results of this current study can be compared. The below sections represents a short synopsis of the current research and understanding on this topic.

Health Literacy

For those with health concerns for their children, understanding the health information they are given is essential in order to make the best decisions and understand their treatment options. However, this is not always possible. Understanding complex health information, or having a high health literacy, can be difficult. According to the Center for Disease Control health literacy is "the degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions" (2016). There are many variables that may contribute to lower rates of health literacy, including demographics, which need to be considered when understanding parents/caregivers as users or readers of health information.

Seeking health information is a common practice with the myriad of health content available on the Internet. However, the information available does not always meet the needs of every individual who comes across it. According to Risoldi et al., almost half of U.S. adults have a hard time comprehending complicated written topics in general. In a comparison study, researchers found that the commercially funded sites (as opposed to U.S. government funding sites) were pointedly more challenging to read. However, it was noted that the readability for both

categories of sites were very poor, both using a reading level too high to accommodate the general public (Risoldi Cochrane, Gregory, & Wilson 2012).

Using sites that are not written with the user in mind may lead to the users avoiding seeking information online altogether. In fact, several studies have reported that people with lower health literacy are less likely to use the Internet as a source to seek out health information (Jensen et al. 2010). This could be due to users' perceived lack of ability to find and understand the health information they are looking for, or a lack of access and knowledge of the resource available for use. Additionally, people with lower health literacy were less likely to be proactive in overall health information seeking, and researchers suggest that this group may be more susceptible or less objective to communication messages from the media they come across (Strekalova 2014).

Lack of awareness of the best websites to find information can lead to individuals reading information from untrustworthy sources and coming to conclusions that may endanger their health. Additionally, when even the best sources fall short in meeting the needs of specific user groups, many may turn to family and friends, as opposed to health care professionals, in order to meet their information seeking needs.

Information Needs of Caregivers of Children Diagnosed with Cancer

During the initial diagnosis stage, when a child is found to have cancer, parents are under an extreme amount of emotional and mental stress, and it is up to hospitals like PCH to provide the most appropriate information. First, however, it is essential to determine what the parents' needs are in terms of information and content, and where they are most likely to seek this out.

Being a caregiver for a sick child or even an aging parent, can be difficult, especially when that caregiver has no medical knowledge or training, as usually is the case. Therefore, a caregiver might turn to the Internet in order to obtain information on complicated topics, like drug information or treatment options. Parents, in general, were found to use the Internet frequently for health information about their child. Most reported in a Pew Research Center survey that the information found usually gave them a sense of relief, due to possibly finding that some behaviors or symptoms are normal (Stern, Cotton, & Drentea 2012). Parents have also reported using the Internet in order to be prepared prior to a pediatric visit, usually when their child already has a diagnosed acute condition. They typically sought information through general websites like Google or Wikipedia, but reported trusting websites run by doctors the most (Sebelefsky, et al. 2015).

However, a 2012 study found that parents with a child who has cancer did not turn to the Internet or other outside sources for information. Most parents claimed that online sources were untrustworthy, and caused fear and general feelings of being overwhelmed by the amount of information out there. If they were to go online it was to clarify information about a treatment or medical term already introduced to them by their physician (Gage and Panagakis 2012). This last statement echoes the findings above that parents with sick children do use the

Internet in conjunction with doctors' visits but there appears to be limited information-seeking usage beyond this. The parents did report using the Internet instead as a tool to update family and friends about their child's condition via social media as well as connect with others who are or have been in similar situations. Both uses were reported as ways to find social support for themselves (Gage and Panagakis 2012).

Overall, studies show that parents of children with cancer place a great emphasis on emotional needs and support, as opposed to information seeking. However, little has been stated about the specific type of support most needed by parents and at what time it should be offered by their providers. A 2014 study looked at the perspectives of parents of children with cancer regarding their psychosocial needs. First, it was found that at the initial diagnosis stage, parents were solely focused on the needs of the diagnosed child and were not able to comprehend or even consider any emotional intervention. Only after a period of time where a sense of routine could be established was psychological needs, of the parents as well as other children, considered. Second, it was discovered that parents desired to connect and speak with other parents who were or had been in the similar situation for both practical matters as well as the emotional aspects. While some parents reported that during the very initial stage of diagnosis this type of communication would have gone unreceived, the importance that communication with other parents happen in the early stages was emphasized. Lastly, it was stated by parents in this study that any emotional interventions done for the sole benefit of the parents would have gone unaccepted if offered too early in the cancer treatment of their child. A general range of two to six months was obtained as a reasonable time after being diagnosed where parents would be willing to think of their own wellbeing. While parents were open to the idea of emotional support interventions including technology, they expressed the need for any technology to coincide with in person support sessions. The researchers' emphasis that any psychological intervention should be flexible and tailored to that particular family in order to meet the needs of the caregivers (Hocking et al. 2014).

Methods

I used content analysis as the research methodology in this study to ascertain what recommendations would be most appropriate for PCH. I used two sources for analysis: informative documents provided to parents by The Emily Center Library at PCH and interviews conducted with three Hematology/Oncology nurses. I then coded the documents and interviews to define common concepts and ideas in order to identify the focus PCH currently has in regards to providing content to parents. I submitted a protocol and received IRB approval in order to conduct this research.

Documents

The documents used are typically provided by The Emily Center Library as a part of packets distributed to the parents at PCH. I asked a library staff nurse for a list of documents that are typically included in each packet created when a new cancer diagnosis is made. These documents are always given to parents in print form and some of the PCH- brand documents do appear on their website. Additionally, all these documents do appear on the new PCH “Journey Board” mobile application which will be discussed later in this report. While the packets are as individualized as possible based on the specific diagnosis and the needs of the families, the library staff nurse recommended the below nine documents as ones that might appear in a variety of cancer packets and that contain the most vital and important topics that all parents should know.

- *About Chemotherapy (PCH)*
- *How to Avoid Infections (PCH)*
- *Bone Marrow Aspiration (PCH)*
- *A Day in the Hospital (Hematology/Oncology) (PCH)*
- *Side Effects of Chemotherapy and How We Treat Them (PCH)*
- *Health Tip Sheet: Basic Hygiene Practices*
- *Learning & Living with Cancer*
- *Coping with Childhood Leukemia and Lymphoma*
- *Frankly Speaking About Cancer: What Do I Tell the Kids?*

These documents include both content produced by PCH, as well as other content produced by outside organizations. As previously stated, all content is printed as individual document for parents, including the outside content. I coded all nine documents to identify common concepts and themes across the PCH provided health information.

Interviews

I conducted three semi-structured interviews with nurses from the Hematology/Oncology department at PCH. I chose to interview nurses as they typically have extensive and close contact both with the patients and parents, and therefore would be able to provide the most in depth information about parents’ needs and levels of health literacy. I recruited participants through The Emily Center Library at PCH. A library staff employee informed the nurses of the research study, and I then contacted the willing participants via email to provide further information and set up interview times. I conducted three interviews over the span of two weeks. The interviews took approximately 45 minutes to an hour. I had a prepared set of topics and questions, and, based off the responses, asked any relevant follow up questions as needed. I recorded the interviews using an audio/voice recorder which was then converted into a written transcript of the interviews. The written transcript was used for coding along with the documents obtained from The Emily Center Library.

Coding

I conducted qualitative coding on both the nine obtained documents and the interview transcripts. I used the software QDA Miner Lite to complete all of the coding. The goal of the coding was to ascertain common concepts and ideas in order to identify the focus PCH currently has in regards to providing health content to parents. For the documents, I used a descriptive coding method in that a passage, either paragraph or short section of the document, was coded for the overall focus or theme of the entire passage. The descriptive coding method was used for the interview transcripts as well, however, each new thought or idea provided in the response was coded. Therefore, sometimes individual sentences were coded, followed by a complete paragraphs in the interviews. I created individual descriptive codes which were then placed and grouped under larger branching categories that defined the overall themes of the codes. Once the codes were placed, I grouped similar codes together in and then created a category that defined the theme of the grouped codes. For example, codes like Blood Cells or Chemotherapy were placed in the larger category of Medical. I developed broader categories in order to summarize similar groups of codes into one concise label. As the goal was to discover a common focus of PCH's health information, broader categories offered a clearer way to both organize the codes and identify overarching themes. The code books for both the documents and interviews can be found in Appendix B.

Results

Overall the coding of the documents identified an overall focus on medical explanations, followed by discussion and tips regarding emotions and support for parents. The coding of the interviews showed an emphasis on parent education specifically in teaching methods employed by the nursing staff, followed by discussion on hospital support resources.

Documents

Appendix A shows the overall coding frequencies for the documents provided by The Emily Center. I found six overall categories and 34 individual codes. Overall Medical and Emotions ranked in the top four most frequent categories, followed by Hygiene in the fifth place as shown in *Table 1*.

Frequent Codes

The most frequent code is Side Effects which refers to explanations on the typical side effects patients experience when going through cancer treatment. The second most frequent code is Guidance for Parents which refers to discussions as to what parents can do to help a sick child or even the siblings in a family adjust to life after a cancer diagnosis. It should be noted that the most frequent Emotions codes appear in only one or two of the nine cases or documents, while the Medical codes appears in two to three. This is unsurprising as most documents, as expected contained medical details and information. The Hygiene category/ Washing code appears in four overall cases which is the most of any code for the whole document project. All three most

common codes in the Medical and Hygiene category pertain in some way to home care. The side effects of cancer treatment might be equally experienced in the hospital or at home. The Treatment (parents) code involves any instructions for parents when at home and a certain medical situation occurs. For example what to do if their child developed a fever. The Washing code was categorized under Hygiene. This is especially important in any home care instructions and overall avoidance of infection, explaining why this code appears in the most amount of documents overall.

CATEGORY	CODE	DESCRIPTION	COUNT	% CODES	CASES	% CASES
MEDICAL	Side Effects	Side effects of the treatment for cancer	21	11.9%	3	33.3%
EMOTIONS	Guidance For Parents	What parents can do to help both child or sibling go about day to day life	14	7.9 %	2	22.2%
MEDICAL	Treatment (Parent)	What the parent should do if X happens (Home Care)	12	6.8%	2	22.2%
EMOTIONS	Parents' Feelings	Common feelings parents may experience	11	6.2%	1	11.1%
HYGIENE	Washing	Explanation of how and what should be washed-properly (ex. hands)	10	5.6%	4	44.4.%

Table 1: Top five most frequent codes of the PCH Documents

Medical Category

The Medical category in general contains seven different codes most of which were found in at least two documents. The top most frequent codes for this category include Side Effects as discussed, followed by Treatments (Parents) as shown in *Figure 1*. While these codes appear over 10 times throughout the project for the documents, all other Medical codes appear less than 10. As shown in *Figure 2*, however, most of the Medical codes commonly appear in more than two of the cases, consistent with the frequency of the top most common codes.

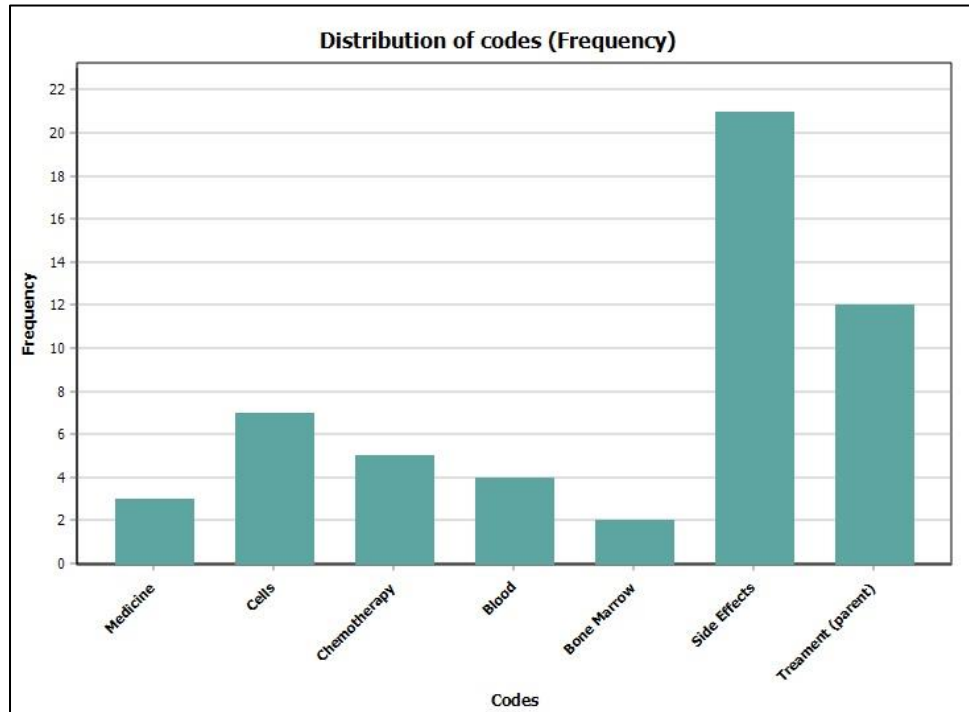


Figure 1: Frequency of Codes overall for the MEDICAL category (Documents)

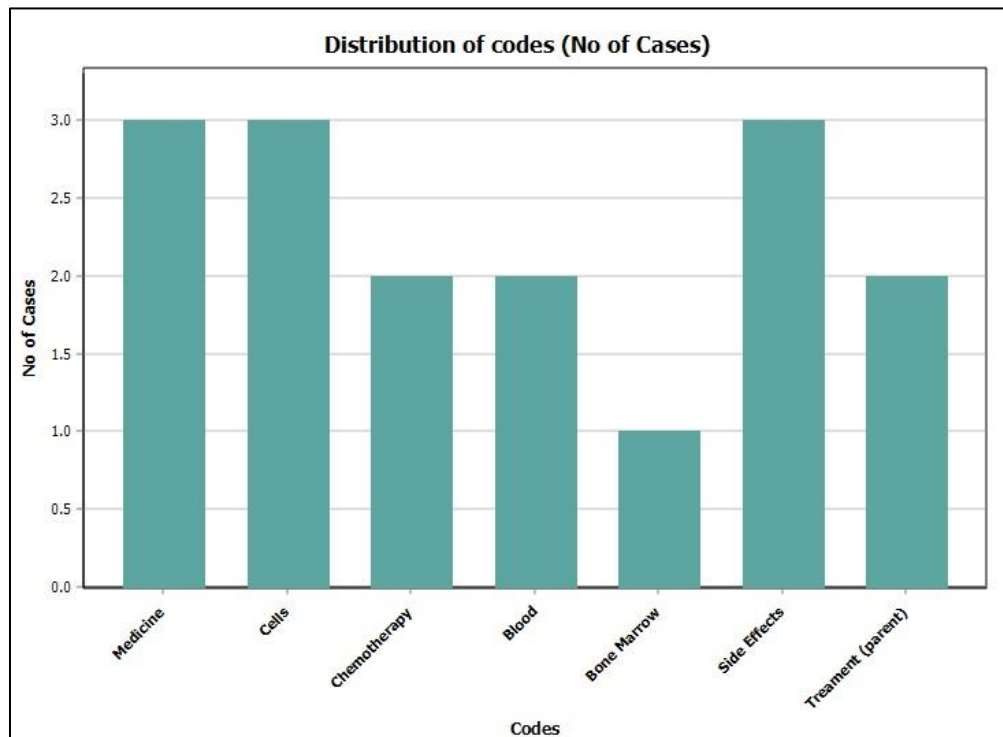


Figure 2: Number of documents each code in the MEDICAL category appeared

Emotions Category

The Emotions category contained 10 different codes found in either one or two documents. As shown in *Figure 3*, the top most frequent codes are Guidance for Parents, Parents Feelings, and Discussions with Others-which refers to guidance outlined for parents on how to talk with the diagnosed child about their illness, as well as other members of the family and friends. I found the Emotions codes in only one or two documents total. Interestingly, while the discussions about what feelings parents might encounter appears frequently, any discussions about how parents might cope with these feelings, coded as Coping (parents) appears half as often. The same occurrence is found in with the codes Child Feelings and Coping (child) referring to what feelings the diagnosis child might experience and how the child might cope with these feelings, either on their own or with the help of the parent.

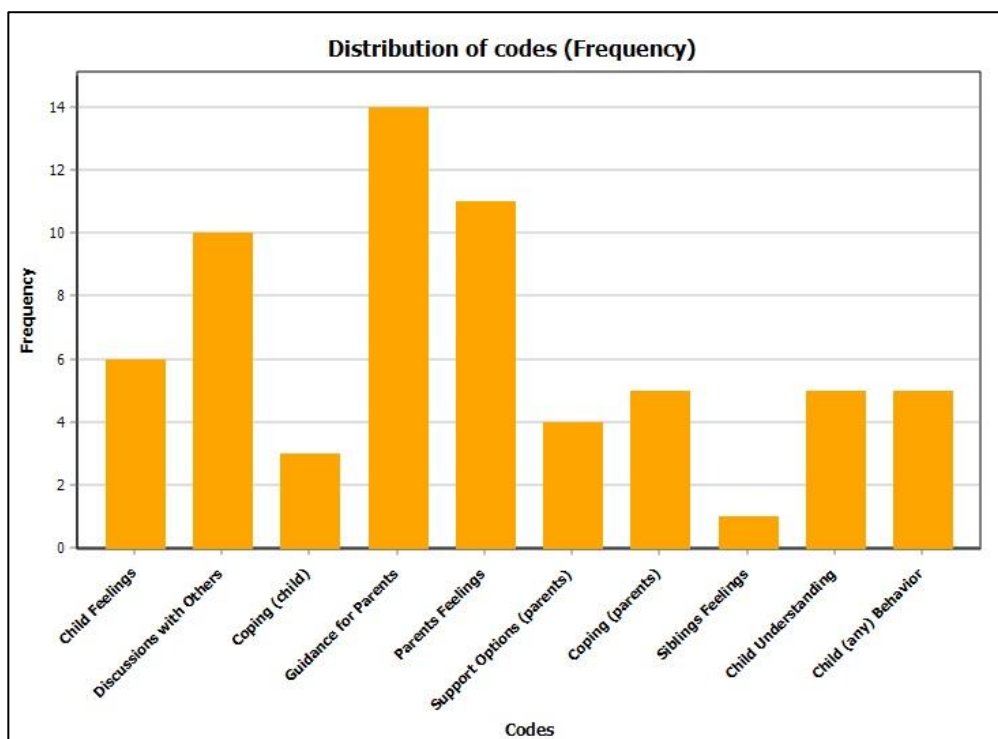


Figure 3: Frequency of Codes overall for the Emotions category (Documents)

Other Codes

All of the remaining codes in the study shows a frequency range from 1-7 and appearing in one to three of the coded documents. This suggests that while there are a wide range of topics covered in the PCH provided documents, none are common enough to be considered a main focus of the content beyond the top five.

Interviews

I coded the interviews in a similar fashion to the documents; descriptive codes were derived from the responses of the nurses and then larger categories were formed to encompass the discovered codes. In using this method of descriptive coding, I found and used different codes than those used for the documents. Additionally, I found less codes and categories compared to those in the documents. The overall results can be found in Appendix A. Four categories were found and 18 individual codes were found. The top four most frequent codes in the interviews can be found below and *Table 2*.

Frequent Codes

Parent Education category was the most frequent category overall, and the top codes include Teaching Methods (nurses), Hospital Support Resources, and Hospital Education Resources. Additionally, the Nurse Duties category is in the top four with Lack of Time to Teach as the most frequent code there. The fifth most frequent code is tied between four others (Overwhelmed, Education Topics, Why They Use the Web, and Type of Questions Asked), all having a frequency count of eight, and therefore not included in *Table 2*. Unsurprisingly, most codes appear in all three interviews with only three codes appearing less frequently.

CATEGORY	CODE	DESCRIPTION	COUNT	% CODES	CASES	% CASES
PARENT EDUCATION	Teaching Method (Nurse)	How nurses help parents learn	12	9.8%	3	100%
PARENT EDUCATION	Hospital Support Resources	Social Work, Child Life etc.	11	9.0%	3	100%
PARENT EDUCATION	Hospital Education Resources	Emily Center, Portal etc.	9	7.4%	3	100%
NURSE DUTIES	Lack of Time to Teach	Mentions how inpatient nurses have limited time to teach	9	7.4%	3	100%

Table 2: Top four most frequent codes of the interviews

Discussion

Background Research

The background research I obtained for this study included several different concepts about the health information needs of parents whose child has been newly diagnosed with cancer. The research showed overall users of information, specifically those with low health literacy, may use the Internet as a source for health information, but were more likely to go on untrustworthy sites or have a more difficult time determining what information is reliable and what information is non-credible.

The literature reviewed also suggested that while caregivers in general may use the Internet quite heavily in their information seeking, parents of cancer diagnosed children reported that going online was something to be feared. Overall, caregivers or parents of relatively healthy children reported using the internet frequently as a source of information, yet parents of children with cancer were fearful of what they might find on the Internet, and were overwhelmed by the seemingly never ending amount of information to go through.

Additionally, parents of children with cancer reported wanting more support options to help deal with the trauma of diagnosis. For example, while many parents of children with cancer did not use the Internet as a source for information seeking they did report using the Internet as a source to connect both with family and friends as well as other parents in similar situations. However, it was suggested by one study that support options should be offered at the right time for parents. During the initial diagnosis stage, any explanation of support options might fall on deaf ears but after time to adjust, many parents reported needing some emotional guidance, including being open to online options.

Emotional Support

The results of the document coding produced similar findings in terms of support. The document coding showed that Emotions category was a very central focus in PCH's material, with Guidance for Parents, and Parents Feelings being in the top five most common codes of the whole project. The documents commonly provided descriptions and explanations about how parents can help their children move through the diagnosis, as well as how they can support them during shifting daily routines. Additionally, the documents regularly provided parents an explanation as to what feelings they might encounter within themselves through the diagnosis process. However, any discussion on how parents might deal with their own emotions or overall cope emotionally with the process, coded as Support options (parents) and Coping (parents), appeared less than half as much as the other top five codes. Also, it should be noted that out of the sampled nine documents coded, only two provided support information.

My coding results for the interviews also showed a heavy focus on the Hospital Support Resources provided to parents and their children. All interviewed nurses felt the support options provided at PCH were very important to their families, however not all discussions of

these options were positive. Two of the three nurses were quoted stating that they were not sure their families even knew or understood what support options were available to them. While it was explained that the families, upon an initial cancer diagnosis, were assigned a social worker to help with the emotional support side of the diagnosis, the nurses still reported families remaining unaware. This could be due how overwhelmed most parents and caregivers can feel when a cancer diagnosis is made. In fact, mentioning how overwhelmed in general parents are was coded at a frequency of eight appearances (coded as Overwhelmed), holding the fifth highest ranking along with three other codes (Education Topics, Why They Use the Web, and Type of Questions Asked). With the amount of printed documents parents are receiving, one nurse speculated that they could become overwhelmed and simply not have the time or desire to read through material, causing some families to remain somewhat unaware of their support options. Similar to the initial background research obtained it was also observed by one nurse that many parents are closed off to the idea of emotional support during the initial diagnosis stage. This nurse stated that it wasn't until at least the first round of chemotherapy had been completed (within one week to one month) that families might start to be more receptive.

While it appears that the PCH is offering their parents a decent amount of support information through avenues like the packets and social work, there appears to be a lack of organization. The limited background research included in this report suggests that emotional support is incredibly important to parents. However as stated above PCH parents are still lacking knowledge of what resources PCH is offering. As one nurse indicated, PCH has the right amount of support resources but there is a clear lack of organization and communication in transmitting those resources to the parents.

Additionally, the interviews with the nurses reflected similar ideas to the background research on parents attempting to connect with other families. All nurses reported observing parents and families wanting to connect with other families either in person at PCH or online through Facebook or discussion boards. One nurse observed that while connecting with other families overall helps with the trauma and stress of a cancer diagnosis as a form of emotional support, there can be some major complications. She mentioned that it is natural for parents to start to compare two children with the same cancer, but as all patients react differently, it can be hard and upsetting to see one child succeeding with treatment while other is not doing so well. All nurses did agree however that overall, connections with other families, either in person or online, appears to be an excellent form of emotional support.

Online Information Seeking

Surprisingly, there was one major difference found between the background research and the coding process. The background research suggests that parents of children with cancer were not open to searching for health information online, whether due to fear, or uncertainty about what they might find. However, all three interviews reported that families go online for their own research quite extensively. "Google is a parent's best friend," reported one nurse. The

nurses reported that many parents still go on the web to search for information for a variety of reasons. One nurse observed that many parents seem to be looking for alternative therapies in addition to the PCH recommended ones. This nurse felt that parents who are frequently doing this are simply trying to look at all avenues in order to help their children. All nurses speculated that the parents might still go online simply for ease of use. One nurse was quoted stating the large amount of printed materials can seem burdensome to go through when the parents simply have one question to answer. Instead it was much simpler and more convenient to type that question into Google and skim through the results than to search through pages of hard copy information. Additionally, all nurses brought up the thought that parents and families were not looking at credible information on the Internet. They observed that many parents would come to the nurse with questions derived from their online research, and these questions frequently dealt with information that was either not medically supported or against what PCH recommends for patients. This implies that parents are not using trustworthy or credible sites on the Internet, and potentially don't know that these websites hold little medical value.

In terms of online use, the background research and my results from the coding showed that parents with a child who has been diagnosed with cancer do use the Internet as a tool for social support. As stated, studies included in the background research observed parents using social media sites in order to connect with family and others in similar situations. The nurses have also observed the same thing from the parents at PCH. However, in both the background research and the nurses' observations it was stated that this Internet use is for strictly emotional support as opposed to health information seeking.

The striking difference between the background research for this study and coding process in regards to parents' online health information seeking was surprising. While the limited background research obtained was relatively new, many of the most relevant articles found were at least four to five years old. As technology progresses it can be surmised that more and more individuals are becoming increasingly comfortable with the concept of online information seeking. This possibility offers some idea as to why parents of children with cancer are being observed using online information more freely. It is possible the ease of access to online information outweighs any sense of fear the parents have about what they might find. Additionally, the background research for this study suggests that parents feel too overwhelmed by the amount of information that is available to them online. However, the parents at PCH appear to use Internet research as way to combat feelings of being overwhelmed by the amount of printed information provided to them. The Internet provides a succinct vehicle for the information while the printed documents have been described by the nurses as cumbersome and bulky. A limitation of this study was time, and therefore a more comprehensive literature review would be needed to provide the more updated and complete image of this issue, as well as an additional study with the parents themselves as participants.

Journey Board Application

Two of the three interviewed nurses did mention the use of a new app developed by The Emily Center that does provide the document information in an online, mobile format. The application is titled “Our Journey with Cancer” which follows the PCH Journey Board throughout a child’s stay within the hospital. Essentially this application can be download to a parent’s phone at no cost, follows the Journey Board and provides links to the documents that accompany each tile of the board. As stated earlier, these documents are the same as the ones typically included in the printed Emily Center packets, however the app is not personalized in any way for the parents and their specific case. For example, the tile or spot on the board titled “We can tell you what treatments will be used” contains the document *About Chemotherapy*, produced by PCH. However, both nurses that brought up the application stated that many nurses and subsequently parents do not utilize the app. They suspected this was due to the nursing staff overall being unfamiliar with it. When asked if parents were observed using the application when it was introduced to them, neither nurse could provide any comment. However, both nurses also mentioned observing parents use sites like Google or PubMed, and therefore it could be inferred that many parents are still not using the application. Additionally one nurse stated that while the application is helpful, it is not searchable like Google, which can hinder usability.

Phoenix Children’s Overall Focus

Overall, while I found and used different codes for the documents and the interviews, both sets of data show a similar focus of information. Side effects of chemotherapy and guidance for parents on how to treat the child were the two most common medical codes in the documents. Essentially these codes deal with home care and disease management. Additionally, all nurses stated that when they are teaching the parents, they are focusing on the management of the disease, and usually are trying to instill on the parents knowledge of how to care for their sick child. When asked what they felt was PCH’s main focus with health information for parents, all three mentioned home care and management as an uppermost topic. Therefore it could be stated that the main focus of PCH, both with documentation and with teaching done by the nursing staff, is the management of the cancer, and instilling on parents the information of how to care for their child at home and away from the hospital.

Similarly the second top codes for both the documents and the interviews dealt with the topic of emotional support. As discussed above the documents offer support information to the parents, and the nurses agree that the support services are a vital part of parents’ journey through the hospital. Overall, while it seems that PCH is attempting to focus on support information, they could be doing more, as only two of the documents included this information and all three nurses felt that parents where not understanding what resources were there for them. Overall my results show that home care and emotional support are at the top of PCH’s focus for parent health information, there appears to be a limitation of how much information PCH can provide when printing the packets.

Phoenix Children's Website

PCH is dedicated to providing their parents accurate and easy to read health information through a variety of means. The Emily Center packets, the Journey Board application, and the PCH website all provide health information. The PCH website itself does present some information to parents about cancer. First there is the Children's Health Encyclopedia which offers general cancer information from treatment to pain management. This information however is not included in the packets given directly to parents. Additionally, there is the cancer page that is done through The Emily Center. This page could be very helpful for parents in that some of the documents provided to parents are linked, three support groups are listed, and some further helpful websites are linked, as well as an explanation as to how to download the app. However, not all of the PCH documents and none of the outside documents are provided on this page. For example, *How to Avoid Infection*, topic stressed as highly important by both the library nurse and the interviewed nurses, is not included on this page. Additionally, this page was located by clicking through several links on the website, specifically: *Health Information>The Emily Center Family Health Library>Health Topics and Patient Education>Cancer*. If cancer is searched in the top right search bar on the PCH website, this page is the 10th result, and the encyclopedia information is the 12th result. If a more specific type of cancer is typed into the search, like leukemia, this page does not even appear on the first page of results.

While this page, and the PCH website in general, offers valuable information for parents, more can be done to make sure the needs of these parents are being met. As mentioned above, parents are actively looking for information online and potentially finding information that is less than credible. Additionally, those with low health literacy are more likely to have a harder time differentiating between credible and non-credible sources. PCH serves a wide range of populations, specifically those who may fit the demographic for lower health literacy. For example, according to the 2013-2015 Community Needs Assessment, about 85% of PCH's population graduated from high school, and about 15% are living below the poverty line (Phoenix Children's Hospital 2015). Additionally, according to the US Census Bureau approximately 74% of individuals (three years and older) in Arizona live in a household with Internet use (2012). Therefore, it is in the interest of the health provider, like PCH, to produce health content via their website in order to provide the best possible resources for their population.

Recommendations

The purpose of this study was to analyze and evaluate the health information content currently provided to parents whose child has been newly diagnosed with cancer at PCH. The goal was to assess the focus PCH currently maintains in their provided health information. I used this information in order to develop recommendations on what content PCH can add specifically to their website in order to meet the needs of these parents.

A summary of the key finding in both the background research, and coding of the documents and interviews can be found below in *Table 3*.

Background Research	PCH Documents	PCH Nurse Interviews
<ul style="list-style-type: none"> • Lower Health Literacy may lead to seeking online information through untrustworthy online sources • Parents whose child has been newly diagnosed with cancer are fearful of using the Internet to seek health information, yet might use the Internet as a tool for emotional support. 	<ul style="list-style-type: none"> • PCH documents have a strong focus on side effects and home care treatment in their health information • PCH has a focus on emotional support for parents, but does not offer a variety of information in their documents. 	<ul style="list-style-type: none"> • PCH nurses focus heavily on teaching parents about disease management and caring for their child at home • PCH nurses state support services are very important to parents and families but express concern over a lack of awareness about them. • Nurses observe parents regularly using sites like Google in order to seek health information, however are not always using credible websites as sources.

Table 3: Key Findings of Research and Study

Cancer Database

The findings suggest that side effects/home care/ disease management is critical and important information for parents to have and is the main focus of PCH's health information. Additionally, the emotional support is vital to parents going through the process of a cancer diagnosis. The PCH website has begun to offer more detailed information for parents to rely on, including online versions of some packet information, and some support services information. I recommend that PCH takes this further by providing a more full and comprehensive cancer database of information for parents to access online. At this point there is a slew of information being handed to the parents via the packets, the website, the Journey Board application, and even verbally from the nurses who are teaching the parents. A complete and comprehensive online database would bring together this information into singular location that both parents and nurses whom are teaching can refer. This database could alleviate some of the overwhelming feelings parents are experiencing during this traumatic time.

Additionally, this database, once more established, could be connected to the Patient Portal where parents are able to assess their child's medical records so that general information and the more personalized medical records are in one convenient location. Also, having the database linked to the medical records would allow PCH to have more personalized information from the database readily available to the parents when they login in to view their records. For

example, if a child is diagnosed with leukemia, specific information could be pulled from the database on leukemia, blood cell information, etc. and appear alongside the medical records. Essentially like an online version of the individualized packets. This would more than likely be set up by The Emily Center at the time of diagnosis so that the information is available immediately.

This cancer database should be searchable. A cancer information database, located clearly and easily on the website would act in the same fashion as Google, offering a search bar that specifically brings up information provided in the documents, or links the parents to the other trusted sites and articles. The current single page on the website with the cancer documents and information, while helpful, is inconvenient to find and not easily searchable on the website. A cancer database that pulls up PCH recommended content quickly and efficiently through the use of specific search tools would be a positive step in both providing parents useful and trustworthy information they can rely on.

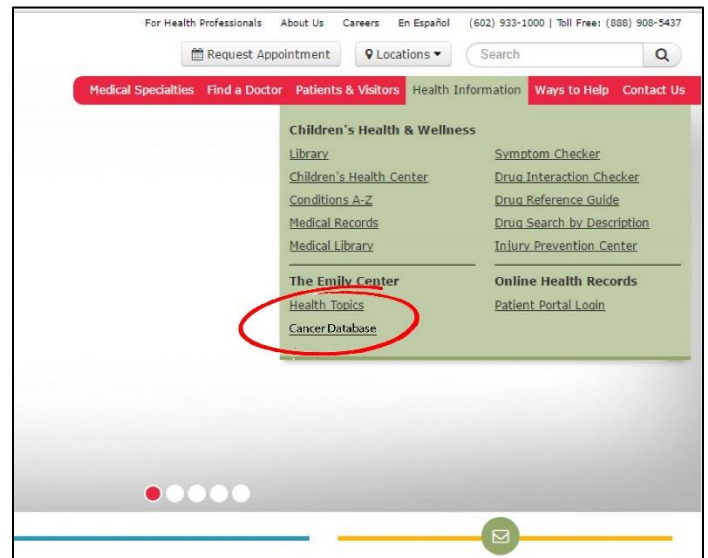


Figure 4: Location of Cancer Database on PCH homepage

Figure 4 shows a potential location for the cancer database link on PCH's homepage so that it is easy to find. Figure 5 below represents a possible format for the database, similar to the format of Google, so that parents will be confident using it.

Home care and disease management is the focus of PCH through both documents and nurse teaching. This database would allow parents to swiftly look up information at home when questions arise, as opposed to searching through the packets or even the application. Additionally, providing a comprehensible and searchable cancer database would allow PCH to produce and/or find even more home care and disease management information. PCH is limited when printing off information for parents, and cannot always provide detailed and specific information, as that would become even more cumbersome for a parent to look through, especially when at home caring for a sick child. It was brought up in a nurse interview that with topics like home care, there are small detailed points that might not get mentioned either in the documentation or in the nurse teaching, due to a lack of time and resources to go through all minutiae. One nurse offer the example of steam cleaning carpets. When a child has cancer, it is recommended that parents do not have their carpets steam cleaned prior to the child going home or when the child is there. This is due to dust and other particles floating into the air due to the cleaning which can cause infection and be very serious for a sick child. This nurse stated that she had a child pass due to infection, and it was believed it may have been caused by carpet cleaning. This small detail and many others might not get stated in the printed

documents nor get brought by nurses during the child's stay in the hospital. However, a comprehensive database, can contain detailed home care information for parents to search.

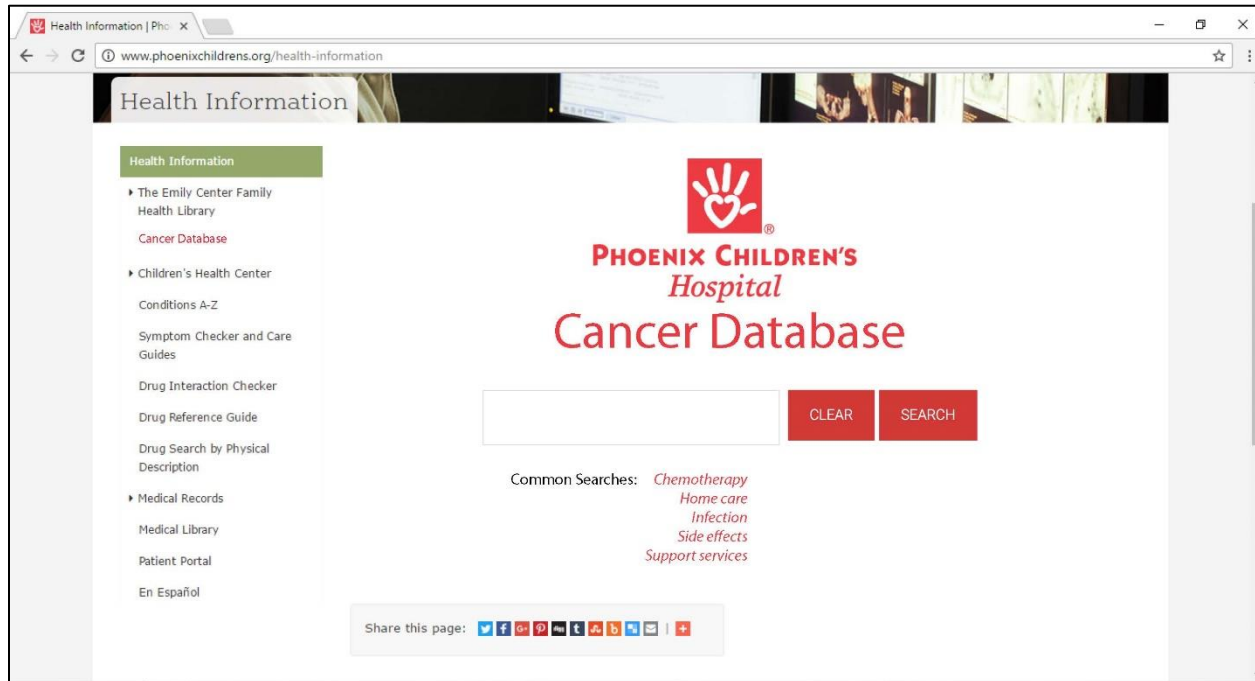


Figure 5: Mockup of how the Cancer Database might appear on PCH's website.

This cancer database would also allow for more multimedia formats currently not possible with the printed packets. One of the interviewed nurses briefly stated observing some families watching YouTube videos in order to see demonstrations on certain home care procedures, like caring for a port. Another nurse stated that many of the families that they encounter are more visual learners, and therefore providing videos on the database would be beneficial for all. The databases could bring up links to recommended online videos, or PCH could use this as an opportunity to produce their own videos so that the parents are getting a more uniform teaching experience.

Another addition to the database would be to offer parents an online, organized and detailed list of support resources available to them both at PCH and in the community. This list should contain a description of the support services and contact information. This list should also be followed by a calendar containing events, support group meetings etc., both within PCH and in the community. This calendar and list would be updated regularly on the website, and would be a part of the cancer database, and therefore searchable for parents. While parents are offered access to a social worker who provides them with further printed documents, a list and calendar that can be quickly skimmed and processed, would allow parents to easily determine what support services they have access to. The background research for this study and nurse interviews suggests that parents, at the time of a new cancer diagnosis, might not be receptive to any emotional support resources, but after a certain time period, become more interested.

By providing this information online, when a parent feels they are ready to seek some emotional support, they have a clear, easy to access document ready for them.

Additionally, as stated above, a database would also allow PCH to offer more guidance for parents on how to handle the emotional side of a cancer diagnosis. They are limited by the print documents, and are only providing a small number of emotional support documents to parents, as compared to other topics provided. I recommend that PCH uses the creation of a database to establish a more complete set of support documents for their families. This might include finding or creating new documents, or joining up with social work and incorporating their information into the database.

Source Credibility

As the findings suggest, parents at PCH frequently rely on the Internet as a source of information. As observed by the nurses, parents are not always finding the most credible information on the web. As PCH's serves a diverse population, low health literacy can apply to many of their parents, which can affect their ability to differentiate credible and trustworthy sources online. Therefore, it is recommended that PCH offer a dedicated article teaching parents about source credibility with online websites. This article would be a simple tool or even checklist parents can use when looking for their own information. This sheet could apply to both medical information, as well as when seeking examples of other families' stories. PCH does offer a list on their website's cancer page of websites to use to seek further information, yet it is also recommended that they go one step further and offer parents a list of common websites to avoid. The source credibility sheet, trusted website list, and websites to avoid list as a whole would help parents navigate the Internet in a confident manner. While it the overall goal would be for parents to rely solely on PCH and the information they provide and recommend, it is impossible to ensure that all parents and families would do this. Therefore, providing those with the best tools seek information successfully would be a positive step for PCH's health information education.

Future Recommendations

Providing the right health information to parents is an ongoing and important process. Therefore, in this last section of my recommendations, I have offered PCH some future research ideas to continue their growth in patient and family education.

First, a common theme among both the background research obtained for this study and the nurse interviews was the concept of parents connecting with other families with children diagnosed with cancer, either in person or online. One nurse felt that this was a great option for parents but had reservations. They mentioned parents felt the need to compare with other families and that can impact these parents emotionally. Overall though, as stated above, support options are a large focus of PCH and this nurse even felt in the right environment connecting with other families is beneficial to parents. I would recommend PCH begin looking into and researching potential ways for parents to connect with others in both a safe and

secure way. It was mentioned in the nurse interviews that PCH did have a program setup for parents to meet in a common area of PCH every Friday. However, due to some inappropriate comments made by some parents, this program was put on a hiatus. I would recommend PCH look into building an online platform within their website, similar to a form of social media for parents to connect. Ideas and comments posted could be monitored by a PCH employee so that any inappropriate posts can be removed.

Additionally, the nurses mentioned the use of the Journey Board application as a great tool for parents, especially those who frequently use their mobile device. However, it was brought up that the app is not searchable and the nurses could not comment on how parents were even reacting to the application or if they were even using it. Another idea for future research would be for PCH to conduct a user experience study on the usefulness of the app in order to see what improvements need to be made. Once a user experience study is complete, a further recommendation would be additional training for nurses on the uses of the application, so that they are more confident in recommending it to parents as a tool for information.

Lastly, an unexpected result of this study found that all three nurses interviewed felt that they had a very limited time to teach the parents or go through the material provided. In fact, Lack of Time to Teach reached the top four most used codes. When discussing the lack of time had all three nurses attributed a cause of this to lack of communication between nursing shifts. It was stated that on each patient chart there is an education box that is supposed to be filled in with the information that shift nurse went over with the family that day, as well as other notes on what the parents might need help learning. However, with the busy day to day duties of the nursing staff, many times this box is left blank, causing the nursing staff to guess at what a parent might know or not know. Additionally, they might spend time discussing concepts with parents that have already been reviewed, which diminishes their already limited time to teach. While this study focused on the content PCH could provide on their website, this unanticipated result bears mentioning. I recommend that PCH start researching solutions to this issue in order to both alleviate the burden on the nurses as well as provide the most organized approach to patient education as possible.

Conclusion

During this study I did have access to The Emily Center documents as well as the nursing staff at PCH. However, I did not have access to the parents or families themselves, which was a limitation. While the nursing staff offered some insight into the parents' thoughts and behaviors, as well as the focuses in health information at PCH, their insight on the families was only based on their own observations. When moving forward with the recommendations in this report, it would be beneficial for additional research to be done with the parents themselves at PCH, so that a more complete understanding of their needs could be obtained.

I conducted this study in order to analyze both the needs for parents whose child has been diagnosed with cancer and the health information PCH is currently providing to their families. I

focused on using the research developed from this study in order to make recommendations for PCH's website so that it might become a usable tool for families. Through the recommendations in this report, the parents of PCH will have more convenient, thorough and personalized access to the best health information PCH can provide.

References

- Center of Disease Control and Prevention. (2016). What is Health Literacy? Retrieved from <https://www.cdc.gov/healthliteracy/learn/index.html>
- Gage, E. A., & Panagakis, C. (2012). The devil you know: parents seeking information online for paediatric cancer. *Sociology Of Health & Illness*, 34(3), 444-458. doi:10.1111/j.1467-9566.2011.01386.x
- Hocking, M., Kazak, A., Schneider, S., Barkman, D., Barakat, L., & Deatrck, J. (2014). Parent perspectives on family-based psychosocial interventions in pediatric cancer: a mixed-methods approach. *Supportive Care In Cancer*, 22(5), 1287-1294. doi:10.1007/s00520-013-2083-1
- Jensen, J. D., King, A. J., Davis, L. A., & Guntzviller, L. M. (2010). Utilization of Internet Technology by Low-Income Adults: The Role of Health Literacy, Health Numeracy, and Computer Assistance. *Journal Of Aging & Health*, 22(6), 804-826. doi:10.1177/0898264310366161
- Phoenix Children's Hospital (2015). Community Health Needs Assessment 2013-2015. <http://www.phoenixchildrens.org/sites/default/files/PDFs/community-health-needs-2013v2.pdf>
- Risoldi Cochrane, Z., Gregory, P., & Wilson, A. (2012). Readability of Consumer Health Information on the Internet: A Comparison of U.S. Government-Funded and Commercially Funded Websites. *Journal Of Health Communication*, 17(9), 1003-1010. doi:10.1080/10810730.2011.650823
- Sebelesky, C., Karner, D., Voitl, J., Klein, F., Voitl, P., & Böck, A. (2015). Internet health seeking behaviour of parents attending a general paediatric outpatient clinic: A cross-sectional observational study. *Journal Of Telemedicine & Telecare*, 21(7), 400-407. doi:10.1177/1357633X15583431
- Stern, M. J., Cotten, S. R., & Drentea, P. (2012). The Separate Spheres of Online Health: Gender, Parenting, and Online Health Information Searching in the Information Age. *Journal Of Family Issues*, 33(10), 1324-1350. doi:10.1177/0192513X11425459
- Strekalova, Y.A. (2014). Seekers and avoiders: Using health information orientation to explore audience segmentation. *Journal of Communication in Healthcare*, 7(3), 228-237. doi:10.1179/1753807614Y.0000000058
- US Census Bureau. (2012). Computer and Internet Use. Retrieved from <http://census.gov/topics/population/computer-internet.htm>

Appendix A

CATEGORY	CODE	COUNT	% CODES	CASES	% CASES
MEDICAL	Medicine	3	1.7%	3	33.3%
	Cells	7	4.0%	3	33.3%
	Chemotherapy	5	2.8%	2	22.2%
	Blood	4	2.3%	2	22.2%
	Bone Marrow	2	1.1%	1	11.1%
	Side Effects	21	11.9%	3	33.3%
	Treatment (parent)	12	6.8%	2	22.2%
HYGIENE	Washing	10	5.6%	4	44.4%
	Avoiding germs (people)	4	2.3%	3	33.3%
	Food Safety	3	1.7%	1	11.1%
	Avoiding Germs (outdoor)	1	0.6%	1	11.1%
	Immunizations	2	1.1%	1	11.1%
	Oral care	1	0.6%	1	11.1%
	Avoiding injury	1	0.6%	1	11.1%
PROCEDURES	Preparation	1	0.6%	1	11.1%
	During	4	2.3%	1	11.1%
	After	1	0.6%	1	11.1%
HOSPITAL	Common hospital tests	4	2.3%	2	22.2%
	Child's room	2	1.1%	1	11.1%
	Amenities	4	2.3%	1	11.1%
	Staff	1	0.6%	1	11.1%
AFTER TREATMENT	Parents	7	4.0%	2	22.2%
	Laws	6	3.4%	1	11.1%
	Needs of the child	7	4.0%	2	22.2%
EMOTIONS	Child feelings	6	3.4%	2	22.2%
	Discussions with others	10	5.6%	2	22.2%
	Coping (child)	3	1.7%	2	22.2%
	Guidance for parents	14	7.9%	2	22.2%
	Parents feelings	11	6.2%	1	11.1%
	Support options (parents)	4	2.3%	1	11.1%
	Coping (parents)	5	2.8%	1	11.1%
	Siblings feelings	1	0.6%	1	11.1%
	Child Understanding	5	2.8%	1	11.1%
	Child (any) Behavior	5	2.8%	1	11.1%

Coding results of the PCH documents

CATEGORY	CODE	COUNT	% CODES	CASES	% CASES
PARENT EDUCATION	New Diagnosis (Doctor)	6	4.9%	3	100.0%
	Hospital Education Resources	9	7.4%	3	100.0%
	Education Topics	8	6.6%	3	100.0%
	Teaching Method (Nurse)	12	9.8%	3	100.0%
	Hospital Support Resources	11	9.0%	3	100.0%
PARENT BEHAVIOR	Parent Relationship with Staff	5	4.1%	3	100.0%
	Vulnerable	1	0.8%	1	33.3%
	Overwhelmed	8	6.6%	3	100.0%
NURSE DUTIES	Mediating	6	4.9%	3	100.0%
	Lack of Time to Teach	9	7.4%	3	100.0%
	Communication w/ Other Nurses	4	3.3%	2	66.7%
PARENT INFO SEEKING	What They Search for Online	5	4.1%	3	100.0%
	Websites Used	7	5.7%	3	100.0%
	Other Families	6	4.9%	3	100.0%
	Non-Credible	4	3.3%	3	100.0%
	Why They Use the Web	8	6.6%	3	100.0%
	Use of the App	5	4.1%	2	66.7%
	Type of Questions Asked	8	6.6%	3	100.0%

Coding results of the interviews with nursing staff

Appendix B

CATEGORY	CODE	DESCRIPTION
MEDICAL	Medicine	explanation of how a medicine works/interacts with the body
	Cells	explanation of how cells work (basic)
	Chemotherapy	explanation of what chemo does
	Blood	what is happening to blood/blood cells, during cancer
	Bone Marrow	what is bone marrow/what is happening to it
	Side Effects	side effects of the treatment (chemo) for cancer
	Treatment (parent)	What the parents should do if X happens
HYGIENE	Washing	explanation what and how to wash X properly
	Avoiding germs (people)	avoiding germs associated with people, ie. sickness etc
	Food Safety	proper food prep
	Avoiding Germs (outdoor)	avoiding germs associated with outdoor environments, excluding people
	Immunizations	what vaccines to get, why
	Oral Care	mouth care, brushing teeth etc
	Avoiding Injury	avoiding getting scraps, cuts etc why
PROCEDURES	Preparation	what to expect when preparing for a procedure in the hospital
	During	what to expect during a procedure
	After	what to expect after a procedure
	Common Hospital Tests	explanation of common hospital tests a family might encounter during their stay
HOSPITAL	Child's Room	what's in the child's hospital room
	Amenities	what amenities are available at PCH
	Staff	explanation of common hospital staff
AFTER TREATMENT	Parents	what parents should do for the child (non-medical, non-emotional)
	LAWS	laws to be aware of after the child is complete with treatment, laws that protect the child
EMOTIONS	needs of the child	non-medical needs of the child (ie school)
	Child Feelings	common feelings a child may experience who has cancer
	Discussions with Others	how to discuss the cancer diagnosis with the child, siblings relatives etc (for parents)
	Coping (child)	Helping the child cope with their feelings
	Guidance for Parents	what a parent can do to help both child and sibling go about day to day life
	Parents Feelings	common feelings a parent might have when their child is diagnosed with cancer
	Support Options (parents)	for the parents
	Coping (parents)	how the parents can cope with their feelings
	Siblings Feelings	common feelings a sibling may have when a brother or sister is diagnosed
	Child Understanding	how any child, based on age, understands "cancer"
Child (any) Behavior	how a child (sick or otherwise) might act when a cancer diagnosis is in the family	

CATEGORY	CODE	DESCRIPTION
PARENT EDUCATION	New Diagnosis (Doctor)	what is told to parents at the new diagnosis stage-by the provider
	Hospital Education Resources	Emily center, portal, etc
	Education Topics	general explanation of the topics discussed with parents, in terms of education
	Teaching Method (nurse)	what methods nurses uses to help parents learn
PARENT BEHAVIOR	Hospital Support Resources	social work, Child Life
	Parent Relationship with Staff	how are the parents interacting with staff
	Vulnerable Overwhelmed	mentions how vulnerable parents are during the process mentions how overwhelmed parents can get
NURSE DUTIES	Mediating	mediating between parents and providers, or general acting as a mediator for parents
	Lack of Time to Teach	mentions how inpatient nurses have limited times to teach
	Communication w/ Other Nurses	with other nurses(charting, education)
PARENT INFO SEEKING	What They Search for Online	topics, medical or non
	Websites Used	examples mentioned
	Other Families	both online and in person in the hospital
	Non-Credible	mentions that what parents find online is usually not reliable info
	Why They Use the Web	what drives parents to seek online info
	Use of the App	mentions parents using the app, or wanting parents to use the app
	Type of Questions Asked	what are the parents asking the staff about

Codebook for Interviews