Bridging the Information Gap: Assessing the Medical Information Needs of Families at The Children's Inn

Tyler Moses

National Library of Medicine Associate Fellow

Date of Submission: August 24, 2017

Project Sponsors: Cathy Morales, Aisha Campbell, and Mallory Lewis

Acknowledgements

Table of Contents

Abstract

Background

Families who have children with rare or undiagnosed diseases struggle to locate credible health information related to their child's case because of a lack of published literature on their condition. The goal of the project was for the Associate Fellow and Project Sponsors to assess the information needs and challenges of the residents of The Children's Inn, the type of resources they use to acquire health information, and how they access the information.

Methods

Throughout March, the Associate Fellow observed the activity occurring at The Children's Inn by participating in scheduled events as well as watching the interactions between the staff and the families from the front desk. From May-June, the Associate Fellow interviewed thirty-three families, eight patients, twenty-one volunteers, eight Children's Inn staff members, and five social workers. In addition, a focus group was held with three family members and one patient.

Results

The rarity of the children's conditions drives families to locate any possible resources that can provide relevant information. This drive can contribute to the families' medical exhaustion related to their search to find answers to their child's medical condition. Along with clinicians, families often employ search engines during their research to yield the most results. However, it is difficult to determine what resources are credible and some families are unsure of how to start the research process. Also, the proficiency to locate information online varies by families. While families learn about NIH resources once they come here, they may find the information too generic or irrelevant.

Conclusions

Health topics identified from the interviews and focus groups can be used to map out potential resources (both physical and electronic) that could populate the tool. Also, information needs can lead to creating new resources to meet the needs that exist after electronic resources are provided.

Introduction

The Children's Inn is a hospitality house located on the National Institutes of Health's (NIH) campus that provides housing for seriously ill children and their families who are participating in clinical research trials. Along with housing, The Children's Inn provides educational services, program activities, and networking opportunities for both the families and children that reside there. The predominate goals of the Spring 2017 project "Facilitating Access to, and Understanding of Medical Information for Patients and Families Staying at The Inn", was to assess the medical information needs and challenges of the families and patients, identify potential resources that would fulfill those needs, and develop a tool or software system that would provide access to those resources while on and off-site of The Children's Inn. The Associate Fellow, Tyler Moses, worked with the three project sponsors, Cathy Morales (Chief Program and Services Officer), Aisha Campbell (Assistant Director of Program Operations), and Mallory Lewis (Assistant Director of Resident Services).

Background

The rarity of certain diseases prevents healthcare professionals from accurately diagnosing a patient's condition; this scenario often causes the patient to seek information on his/her condition based on the symptoms which yields many inconclusive results (Spring, 2014). Simultaneously, patients as well as parents and caregivers of children with rare disease may perceive health practitioners as insufficient information resources for their lack of awareness of rare diseases (Anderson, Elliott, & Zurynski, 2013; Pelentsov, Fielder, Laws, & Esterman, 2016; Pelentsov, Laws, & Esterman, 2015).

Due to the lack of medical information from healthcare practitioners, patients with rare diseases rely on the Internet or their social network to acquire pertinent information in hopes of self-diagnosing their condition (Spring, 2014). Once their diagnosis is uncovered, patients along with parents or caregivers of children diagnosed with rare diseases become their own health experts by documenting their medical experiences, researching clinical trials they can participate in, acquiring any credible resources they come across, and sharing the information with others through various mediums (i.e. social media) (Pelentsov, Fielder, Laws, & Esterman, 2016; Anderson, Elliott, & Zurynski, 2013; Spring, 2014).

However, being the sole expert on their medical condition presents unique challenges. Those with smaller social networks find it more challenging to locate relevant resources regarding their condition (Askelson, Campo, Carter, 2011). Patients from rural communities or who are limited-English speakers may have limited access to health information or lack the skills to navigate online medical resources to locate health information (DeHoff, Staten, Rodgers, & Denne, 2016; Eneriz-Wiemer, Sanders, Barr, and Mendoza, 2014).

Along with the issues of locating appropriate health information, the lack of published research complicates patients', caregivers', or parents' ability to make informed medical decisions. For example, parents are mainly concerned with finding relevant information on therapeutic services for their children and comprehending how the illness will impact their child's development (Pelentsov, Fielder, Laws, & Esterman, 2016; Pelentsov, Laws, & Esterman, 2015). Specifically, they are seeking information that is related to their specific case (Pelentsov, Laws, & Esterman, 2015). Such information is essential in assisting children with a rare disease to learn how to maintain their health as well as learn how to transition from pediatric care to adult health services (Zurynski & Elliot, 2013; American Academy of Pediatrics, 2011).

Methodology

Prior to initiating the project, it was segmented into four phases:

1. Information Gathering
2. Road Mapping
3. Design and Usability
4. Final Testing and Launch

Due to the limited time of the spring project phase of the Associate Fellowship Program, the Associate Fellow and Project Sponsors focused predominately on Phase 1: Information Gathering which focused on gathering information on the medical information needs and challenges of the pediatric patients and the families/caregivers.

To acquire the data during this phase, the Associate Fellow used methods from the qualitative research approach (e.g. observations and interviews) to acquire data on the information needs and challenges of the residents at The Children's Inn from the perspective of the families, children, social workers at the Clinical Center, and staff and volunteers at The Children's Inn. Qualitative research approach is where the researcher works to interpret a behavior or event from the perspective or culture of a select group of individuals; the benefit of this approach is that the researcher can better understand the group being researched and define a problem that is unclear at the beginning of the study (Labaree, 2017). While there is some data in the published literature about the health information challenges of the families who have children with rare diseases, the Associate Fellow and Project Sponsors wanted to pinpoint what needs, challenges, and health topics of interest were unique to residents at The Children's Inn which aligned with the goals of the qualitative research approach.

Observations

The Associate Fellow observed the activities of the families at The Children's Inn from March 13th-29th. During this time, the Associate Fellow watched the interactions between the staff and families from the front desk at the entrance to The Children's Inn and attended several scheduled programs. The objective of the

observations was to learn about the culture of The Children's Inn, establish preliminary knowledge about possible medical information needs, and introduce the Associate Fellow to families at The Children's Inn. The front desk observations where done in four intervals for about two days out of each week. For the program observations, the Associate Fellow selected a diverse number of program activities to attend to see how the staff, children, and parents interacted with one another. Notes for each observation session were recorded in a contact form (see Appendix A for an example).

Interviews

Between May 8th-June 23rd, 2017, the Associate Fellow interviewed 33 families, 8 patients, 21 volunteers, 8 staff members, and 5 social workers; families who stay at The Children's Inn are asked to sign a Disclosure of Information and Consent Form which allows people visiting The Children's Inn to document and speak with the families. The objective of the interviews was to gain a perspective as to the medical information needs of the residents, difficulties that they experience with obtaining information, what resources residents frequently consult for new information, and if there were any topics or resources that they desired to know more about; the Associate Fellow spoke with the staff and volunteers of The Children's Inn to gauge if they noticed the information needs of their residents, assess their willingness to connect residents with health information, and figure out what kind of information retrieval tool would be suitable for the residents. The Associate Fellow along with Aisha Campbell interviewed four social workers including the Chief of Social Work at the Clinical Center who work with families at The Children's Inn; the objective of the interview was to uncover what information needs they have observed from the families and any issues that they feel families may have with accessing health information. The inquires utilized in the interviews were designed by the Associate Fellow and revised with the assistance of the Project Sponsors and Kathel Dunn, the Coordinator of the Associate Fellowship program at NLM. Notes from the interviews were also recorded in the contact forms used for the observations. The questions used in the interviews are in Appendices B-E.

Focus Group

Like the interviews, the objective of the focus group was to acquire additional data about the health information needs of the families and children residing at The Children's Inn. The discussion-based format of the focus group would allow participants to build ideas from one another's responses and hopefully produce new ideas that have not been heard during the interviews. The focus group took place on June 21st, 2017. Three family members and one patient participated in the focus group. The group consisted of two international families, one of which spoke Spanish and whose daughter was a bilingual patient staying at The Children's Inn. The Project Sponsors reserved the space, provided snacks and drinks for participants, and recruited people to take part in the focus group; Aisha Campbell and Mallory Lewis further assisted in the focus group by serving as a moderator and

notetaker, respectively, while the Associate Fellow served as the facilitator. Also, Rosa Segura, the Residence Service Manager at The Children's Inn, served as a translator for Spanish-speaking participants. The Associate Fellow created the questions and script; they can be found in Appendix F.

Results

Issues with Finding Information

In observations, interviews, and focus groups patients, and families all mentioned recurring issues of: understanding the published medical articles and information from ClinicalTrials.gov, locating credible sources, finding relevant information that is applicable to their child's condition, and being able to find federal resources prior to coming to NIH.

When searching the biomedical literature, families have found that scholarly literature provides more accurate information on their children's condition. However, families feel that the medical terminology makes the information not comprehensive to the public. Families search for relevant clinical trials to enroll their children that are either close to their home state or someplace that is accessible through means of transportation. However, the organization of the content in the resources makes it difficult to locate and distill the information on clinical trials run by health-related federal institutions. Other than individual searches, families learn about NIH and/or of a clinical trial conducted at NIH predominately from a third party (e.g. a friend, a patient created website, etc.) (6) or from their local physician (8).

Families heavily rely on search engines, specifically Google, to pull information on their child's condition. The searches often yield little or irrelevant information related to their child's case because of the rarity of the disease; from the small number of results pulled up, families often struggle to determine if the resource is credible. Searches may also produce too many results which causes families to feel overwhelmed by the volume of information that they need to shift through. Search engines are also employed to define medical terms, find relevant medical articles, and locate places for treatment. During the focus group, participants specifically mentioned that they use keywords within search engines that are based on new information from medical resources or the type of information they are seeking. Outside of search engines, families turn to both websites generated by federal, private, and non-profit institutes. However, families have often noted that they are not aware of all the possible resources accessible to them until they physically come to NIH to enroll their child into a clinical trial; even after this, the social workers have noted that families may only be aware of resources produced by the institution that they visit for treatment.

Years spent searching for answers or having a medical background make families proficient searchers who know which resources to use and can understand medical research. However, not all families at The Children's Inn know how to

search for information. Issues that may impede their ability to research information range from not knowing how to use keywords, lack of clarity as to what questions to ask during medical visits with the NIH physicians, and a lack of resources to search for information. Another barrier mentioned by the participants is that the medical terminology used in information given from the NIH physicians or from the medical articles make the content uncomprehensive to the public; additionally, some families may not have access to resources to define medical terms.

Information Needs

Some of the information needs that were evident from all groups were: the desire to form a social network, having the capability to access health information from multiple data sources, having access to extract health information from more diverse channels, and having multiple sources of information in one central location.

Aside from the biomedical literature, NIH websites, and consumer health websites, families use social media support groups, medical foundations, colleagues and friends, and medical conferences to find information that could help improve their child's condition. Families feel the need to establish a network, electronic or in person, with people who comprehend the trails of caring for a child with a rare disease; the network is especially advantageous if people they are connected to are caring for a child with the same diagnosis. However, families within the focus group have cautioned against using support groups for new health information as it may not be credible. Also, F1 noted that the support groups she turned to online consisted of cliques that were not receptive to new people.

Families, staff, and volunteers have noted that families expend a lot of effort searching for information resources. Families find this process to be time consuming and not all families like relying on Google as a means of gathering health information. Families want all the information they need to be in one central location to mitigate the effort spent searching as well as to simplify the process of distilling and comparing information from other resources.

For young adult patients at The Children's Inn, they spoke of needing to understand how to compare and apply for health insurance once they are no longer eligible to be covered by their parent's insurance. The young adult patients also expressed an interest in learning how to shift from pediatric to adult healthcare services, apply for disabilities benefits, and make informed decisions about their medical care along with needing lifestyle information (i.e. applying for college, networking opportunities, and budgeting) that could help them transition into adulthood.

Some health topics that families expressed an interest in were:

- Coping with grief and loss
- Exercising safely
- Nutrition as a form of treatment

See the List of Health Topics of Interest Excel spreadsheet in the 2016-2017 Associate Fellow's report folder in Sharepoint for more health topics and in what context they were mentioned.

Experiences Specific to Families with Rare or Undiagnosed Conditions

The experiences that were specific to families with rare or undiagnosed conditions were: families serving as experts in their child's condition, their desire to have an overview of the condition itself, the rarity of their child's disease makes them unique, families who come to The Children's Inn experience medical exhaustion, and children feel isolated because of their medical condition. See Table 1 for quotes related to these experiences.

Table 1: Experiences Specific to Families with Rare or Undiagnosed Conditions

Theme	Interview Group that Mentioned Theme	Quotes
Families are experts in their child's condition	Families, Focus Group, Staff, and Volunteers	"I think by the time a lot of families get here, they've already done a lot of research."-FG1
Overview of the disease	Families and Patients	"I want to have some basic information like what to expect when it comes to treatment and how it will impact my child."-F5
Families are one in a million because of their health condition	Families, Patients, Staff, and Focus Group	"She's like one in ten million to have this bacteria and genetic mutation." -FG2
Families who come to The Children's Inn suffer from medical exhaustion	Families, Volunteers, and Focus Group	"I mean, when I started my disease, I was in shock and I didn't understand-I didn't know that it was gonna take so long..."-FGP
Children experience a sense of isolation due to being the only ones with their condition	Families, Social Workers, and Volunteers	"It's helpful for the kids, for they are considered rare creatures at home. But here they get to meet someone like them." -F30

Families serve as experts on their child's condition for they have consolidated any information that they have either found or been given over the years; in addition, parents tend to serve as the sole caregivers of their children and their experience, culminated with the knowledge they have acquired, has taught them

how to tend to their child's needs outside of treatments from the clinical trials. While families are experts on their child's condition, they perceive the clinical trials as a means of generating more information on their child's specific case. Topics families are interested in learning more about their child's condition include:

- Progression of the condition
- Life expectancy of their child
- Issues (e.g. environmental, social, or physical) that contribute to a crisis or the emergence of the disease

All the patients that frequent The Children's Inn have conditions that have not been seen before in the medical community. Though there are some patients with commonly known illness, such as leukemia or lymphoma, they are often diagnosed with a secondary medical condition or exhibit a variant of the disease that does not respond to traditional treatment. The rarity of their illnesses also causes the children to feel isolated because they may struggle with identifying with their peers; in addition, patients frequently spend long periods of time in treatment which takes them out of school, further isolating them from their friends, classmates, and some family members.

Prior to coming to NIH, families have already exhausted other means of medical treatment from their home state or from other locations. Thus, families come to The Children's Inn having spent a lot of time searching for answers to the child's medical condition while depleting their financial resources in the process. Once families come to NIH, they perceive the clinical trial as their final chance to learn about their child's disease. This perception combined with the years spent searching for answers has exhausted many families and patients which has taken a toll on their mental health. Some of the medical exhaustion is only alleviated once families begin receiving answers as to their child's condition or their child starts responding positively to treatment.

Information about the Tool

All the groups felt if an information tool would be produced, it must be accessible in various formats; the two most referenced formats were an app and a kiosk. Most interviewees felt an app would be appropriate as many people research information on their phones and would be able to use it to answer additional questions once they return home. A kiosk was mentioned among the interviewees to acknowledge that it would decrease the amount of time and effort it would take to locate electronic sources of health information. In conjunction, any information on it should be organized in logical manner; one format of organization mentioned by the focus group was a top-down format by symptoms, diagnosis, and then condition. Content within the tool needs to be centralized in one place and comprehensive to individuals across various literacy levels. Staff at The Children's Inn felt that it was especially pertinent that the tool be accessible to families once they return home so they could still obtain the information.

While interviewees were mainly interested in health resources with the content in plain language, such as Mayo Clinic, WebMD, or educational videos from YouTube or other sources, families and Children's Inn staff believed that articles from medical journals should be included in the tool. Families in the focus group noted that there should be a guide illustrating how to use the tool. Though there was a consensus amongst social workers and families to include links to support groups, patient support foundations, and organizations that work with patients undergoing clinical trials in the tool, families participating in the focus group felt that they should only be used as a means of receiving emotional support instead of getting information.

All five groups felt that a variety of websites from credible federal and non-federal institutes should be included in the tool. NLM-produced websites that were specifically mentioned as potential resources were:

- PubMed
- MedlinePlus
- Clinicaltrials.gov
- NLM's main webpage
- MedlinePlus Magazine
- Genetics Home Reference
- Resources for caregivers listed by the Specialized Information Services (SIS) Division of NLM

Any non-federal resources used in the tool should have its own section with a subheading. An additional resource mentioned by those in the focus group was the inclusion of a list of websites to research medical conditions.

The type of content that families wanted to see in the tool included: a condition's diagnosis, symptoms, and medical practitioners of interest based on specialties within their fields. Furthermore, some of the resources in the tool should include information related to psychosocial health such as:

- Location of psychologists
- Electronic and physical resources offered through NIH to promote mental health
- How to maintain social networks to prevent feelings of isolation due to medical treatment
- How to make children understand that their medical care is going to be a long process

Though all participants felt that information on nutrition should be included, they noted that the tool would need to include a diverse number of topics to accurately represent all the families' medical information needs. Some of these health topics were: coping with the loss of a child, how to find financial support, basic biology, stress management, consumer information on genetics, and homeopathic remedies to keep kids healthy. Along with specific health topics, the tool should provide

resources pertaining to research such as questions to ask clinicians and researchers to begin searching for information and a listing of search terms to find information.

In terms of marketing the tool, interviewees felt that information about the tool should be both at the Clinical Center as well as The Children's Inn. The best means to provide families information on the tool were: handouts/flyers, advertisements on the video systems at The Children's Inn, word of mouth, announcements through The Children's Inn social media accounts, and as part of the families' check in process. Some of the essential features of the tool noted by all five groups were multilingual content, ability to contact a medical professional to discuss emotional and medical issues, a platform/space where families can connect with one another, and summaries of the content within the tool or about the federal institutes listed that are currently running clinical trials.

When asked, many the interviewees (16) felt that staff at The Children's Inn should assist in connecting families to health information. However, individuals participating in the focus group were concerned about the practically of managing the information since children staying at The Children's Inn have dissimilar conditions. About four volunteers and one staff member were unsure if connecting families to health information was appropriate for The Children's Inn and two volunteers did not see it as a new role that staff should adopt. The interviews with the families revealed that most of the families learn about The Children's Inn from researchers and clinicians running the clinical trials (4), learn about NIH from a friend (2), and hear about the clinical trials from their local medical practitioner (8).

Individuals from all five groups felt that the tool would be mostly used by parents since they will use any means to find information; in addition, people in the focus group and the social workers believed that the tool would benefit patients once they reach a certain age and maturity level. The tool could also serve as a means for patients to seek health support or explore networks where they can receive support.

Discussion

The data from the project showed that there was a lot of overlap amongst all the groups the Associate Fellow spoke with in terms of the information needs and challenges of the families and patients at The Children's Inn. This overlap is significant for it helps identifies what needs and challenges should be focused on if an information tool is be constructed. Also, many of the overlapping themes represent health issues that are seen across individuals with commonly known-chronic diseases.

One thing that was consistent with the published literature was that families truly serve as the main sources of information on their child's condition due to the time and effort spent in researching information as well as compiling all the medical information that they have acquired either from their research or from the medical practitioners running the clinical trial or tending to their child. However, families are

always seeking more information. One thing that was contrary to the published literature was that families and patients heavily rely on medical professionals and clinicians to provide answers about the disease itself. This contradiction could stem from the fact that the goal of the clinical trials that children are participating in are to produce a diagnosis, provide treatment, or yield more information about the condition; therefore, physicians may be viewed as the main medical gate keepers of information. Another thing that was unexpected was that though families are interested in forming social networks to meet individuals who have similar experiences to them, they don't always rely on these networks to pull information; this could be related to issues regarding the credibility of the resources that are pulled.

In terms of the tool, many interviewees felt that it should be predominately used by parents but a few individuals specifically mentioned that patients should be able to use the tool as well. The idea of making the tool useful for patients could stem from the fact that they would need to learn how to maintain their health outside of medical treatment. When they are no longer children, patients need to understand what their condition is and effectively communicate with medical practitioners about their health care.

The Associate Fellow had an opportunity to present on the project to the Project Sponsors and other staff members from The Children's Inn. Much of the information noted confirmed assumptions that staff previously reported about the challenges associated with the process of accessing information for the residents, including that some of the residents already turn to NLM tools, like MedlinePlus and ClinicalTrials.gov, to retrieve data on health topics of interest. The staffs' concerns in providing sources on health information lie with making them more accessible as well as bridging the gap between those who possess a lot of research skills with those who aren't as familiar with searching to decrease the amount of Googling that is done.

While some of these concerns can be mitigated by providing a list of available resources, that is only a partial solution as it will not make the sources easier to navigate nor will it make the content more specific to the families' health concerns. Additionally, there is concern about how to make the tool accessible to families prior to them coming to NIH or once they leave campus. The divergence between families who possess the technical skills and resources to pull information online would not be fully addressed through a tool; there may need to be means of presenting families the same content but in a physical form. Other potential issues that need to be considered with an information tool are: ability to adjust by reading/health literacy level, content that is accessible in all languages represented at The Children's Inn, and limiting access to the tool if it will contain patient information. There should be some consideration as to what other efforts can be done to bridge the gaps like providing workshops on how to identify keywords and search for information on resources like Genetics Home Reference.

Limitations

Since the timeframe of the spring projects is only six to seven months, the project was scaled back so the Associate Fellow and Project Sponsors focused predominately on gathering data on the families' and patients' information needs. Also, there were few young adult patients who were interviewed during the project; these interviews could have illuminated what health topics of interest that were unique to them. The small number of young adult patients interviewed could have been the result of the constant change in the number of residents who stay at The Children's Inn during the week or just that there were fewer young adult patients staying for treatment because of the school schedule.

Recommendations

To proceed with the project, the Project Sponsors would need to take the data about health topics that families and patients want to learn more about and identify what existing resources can match these needs. Sources made from federal institutes (e.g. NLM, National Cancer Institute, etc.) should be distinguished first and then credible sources from private and non-profit agencies. This mapping process would assist the Project Sponsors in detecting what are current credible health resources they can recommend to the residents at The Children's Inn based on their topic of interest. Also, the mapping process can help pinpoint which health topics have few or no sources; the gaps can be an opportunity to generate health content in house and determine which format (i.e. videos, guides, webinars, etc.) it should be. As aforementioned, a working list of these health topics, written in the terms used by those who were interviewed and in what context, can be found in Sharepoint. The content could be generated by working with health content experts, such as those who work on MedlinePlus, and consulting clinicians running the trails as well as families if the Project Sponsors seek to create both general and condition-specific health information. In addition, the Project Sponsors could formulate additional solutions, other than electronic resources, that can be used to address some of the needs unmet by the existing sources of health information; an example of a potential project proposal for the second phase of the project can be found in Appendix G. Lastly, the Project Sponsors should explore existing health information apps, like WISER and MyMedical, produced by both the private and federal sectors to generate ideas as to the design and functions of the tool.

Bibliography

American Academy of Pediatrics. Clinical Report-Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home. Pediatrics [Internet]. 2011 Jul [cited 2017 Mar 1]; 128(1):182-202. Available from www.pediatrics.org/cgi/doi/10.1542/peds.2011-0969.

Akelson NM, Campo S, Carter KD. Completely Isolated? Health Information Seeking Among Social Isolates. Health Education Behav [Internet]. 2011 Apr 1 [cited 2017 Mar 1]; 38(2):116-122. Available from https://doi.org/10.1177/1090198110369055.

Anderson M, Elliott EJ, Zurynski YA. Australian families living with rare diseases: experiences of diagnosis, health services use and needs for psychosocial support. Orphanet J Rare Diseases [Internet]. 2013 Feb 11 [cited 2017 Mar 1]; 8(22):1-9. Available from https://ojrd.biomedcentral.com/articles/10.1186/1750-1172-8-22.

DeHoff BA, Staten LK, Rodgers RC, Denne SC. The Role of Online Social Support in Supporting and Education Parents of Young Children With Special Health Care Needs in the United States: A Scoping Review. J Med Internet Res [Internet]. 2016 Dec 22 [cited Mar 1]; 18(12):1-13. Available from http://www.jmir.org/2016/12/e333/.

Eneriz-Wiemer M, Sanders LM, Barr DA, Medoza FS. Parental Limited English Proficiency and Health Outcomes for Children With Special Health Care Needs: A Systematic Review. Academic Pediatrics [Internet]. 2014 Mar-Apr [cited Mar 1]; 14(2):128-136. Available from https://doi.org/10.1016/j.acap.2013.10.003.

Labaree RV. Organizing Your Social Sciences Research Paper: Qualitative Methods [Internet]. Los Angeles (CA): University of Southern California, Von KleinSmid Center Library for International and Public Affairs; c2017 [cited 2017 Aug 22]. Available from http://libguides.usc.edu/writingguide/qualitative.

Pelentsov LJ, Fielder AL, Laws TA, Esterman AJ. The supportive care needs of parents with a child with a rare disease: results of an online survey. BMC Family Practice [Internet]. 2016 Jul 21 [cited 2017 Mar 1]; 17(88):1-13. Available from https://bmcfampract.biomedcentral.com/articles/10.1186/s12875-016-0488-x.

Pelentsov LJ, Laws TA, Esterman AJ. The supportive care needs of parents caring for a child with a rare disease: A scoping review. Disability Health J [Internet]. 2015 Oct [cited 2017 Mar 1]; 8(4):475-491. Available from http://dx.doi.org/10.1016/j.dhjo.2015.03.009.

Spring H (Health and Life Sciences, York St. John Univ., York, England). Health information, what happens when there isn't any? Information literacy and the challenges for rare and orphan diseases. Health Information & Libraries J [Internet]. 2014 Aug 25 [cited 2017 Mar 1]; 31(3):243-246. Available from http://onlinelibrary.wiley.com/doi/10.1111/hir.12068/epdf.

Zurynski YA, Elliott EJ. Challenges of transition to adult health services for patients with rare diseases. Med J Aust [Internet]. 2013 Jun 17 [cited 2017 Mar 1]; 198(11):575-576. Available from https://www.researchgate.net/publication/255688389.

Appendix A: Contact Summary Form

Contact Date:

Contact Time:

Today's Date:

Weather Conditions during Contact:

Contact Type (check all that apply):

     Observation:

     Meeting:

     Program Visit:

     Interview:

     Phone:

     Other:

Sites:

Activities:

Engaged Contacts at the Site

Name	Title

Notes

Answer the Questions as They Follow:

1. Are there specific things that you want to learn at this contact?

2. Were there any main issues or themes that you noticed during the contact?

3. Were there any issues or themes that you would like to explore further at the next contact?

4. What new or remaining questions have you considered for the next contact with the site?

5. Did the site contact bring forth any new ideas to consider for future steps in the project?

Appendix B: Interview Questions for Families

Explain purpose of being at The Children's Inn and Outcome of the Project

1. What brought you to The Children's Inn?

2. What do you know about your child's illness?

3. Are there any topics or additional information that you would like to know about their illness?

4. Where do you go to find information and how do you get it?

5. What kind of resources do you use or want to know how to use to find information?

6. Do you have any problems with finding information related to your child's diagnosis? If so, what are they?

7. What do you think that families should know about NIH or The Children's Inn prior to coming?

8. Do you have any other comments or ideas about you or your child's health information needs?

9. What questions do you have for me about the project?

Appendix C: Interview Questions for Young Adult Patients

Explain purpose of being at The Children's Inn and Outcome of the Project

1. What are your or your family's main health concerns about your condition?

2. Who in your family spends the most time looking up health information?

3. What information do you want to know about your medical condition?

4. Where do you and your family go to locate health information?

5. Which of these resources provide you with the most crucial information?

6. Do you have any problems with finding information related to your diagnosis? If so, what are the roadblocks or issues?

7. What health information topics and resources would benefit you and your family the most?

8. Do you have any other comments or ideas about your or your families' health information needs?

9. What questions do you have for me regarding the project?

Appendix D: Interview Questions for Staff/Volunteers

Explain purpose of being at The Children's Inn and Outcome of the Project

1. How long have you been working at The Children's Inn?

2. What are your responsibilities at The Children's Inn?

3. What do you feel are the main health concerns of the patients and families that visit The Children's Inn?

4. Are there any health and /or lifestyle information resources and topics that you feel would benefit the patients and families?

5. Do you think staff and volunteers would be interested in connecting residents to health information?

6. What questions might patients and families have about NIH and The Children's Inn before coming?

7. What do families find special about The Children's Inn?

8. Is there anything that you would like to know to help serve the families that stay at The Children's Inn?

9. If The Children's Inn could create a tool to help families/caregivers access information, what type of tool would it be and where should it be located?

10. What types of information mediums would you want to see in the tool?

11. How should this tool be introduced to families and other individuals visiting The Children's Inn?

12. What questions do you have for me regarding the project or the tool?

Appendix E: Interview Questions for Social Workers

Explain purpose of being there and outcome

1. Why do you think patients and families come to The Children's Inn?

2. What are the most common health issues patients having at The Children's Inn?

3. Based on your conversations with the patients and the family members, what kind of information do you think they would be interested in regarding their medical conditions?

4. Where do patients and families go to locate health information?

5. How are patients and families accessing health information?

6. What are some of the issues patients and families encounter when looking for information related to the patient's diagnosis?

7. *Are there any health information resources and topics that you feel would benefit the patients and families?

8. *If The Children's Inn creates a health information tool, what type of tool would benefit patients and families the most?

9. *What type of resource formats should be included in the tool?

10. *Where do you feel that the tool should be located? On the website, as an app, etc.?

11. *How should this tool be introduced to patients and families?

12. *Do you have any other comments or ideas about the health information
    needs of the patients and families or the tool?

13. *What questions do you have for me regarding the project or the tool?

Note: Questions with a * may be removed later based on responses.

Appendix F: Script and Questions for Focus Group

- Purpose
    - Learn of the families' health information needs
    - Learn what kind of information tool/resource/thing would benefit families at The Children's Inn
- Roles
    - Tyler Moses-Facilitator
    - Aisha Campbell-Notetaker
    - Lewis Mallory-Moderator
- Time: 3:30-4:30 pm
- Date: June 21st, 2017
- Location: Large conference room at The Children's Inn across from the drop off for children's summer camp

Script for Focus Group

Introduction

Good afternoon! First, I want to thank you all for taking time out of your day to participate in this focus group.

My name is Tyler Moses and this Mallory Lewis, Assistant Director of Resident Services, and Aisha Campbell, Assistant Director of Program Operations. They are staff at The Children's Inn and are helping me with facilitating this focus group.

I am working with the staff at The Children's Inn on an information resource project. The goal of the project is to create a tool that will help connect you and families at The Children's Inn to health information. The purpose of this focus group is to learn of any health information needs you may have and what kind of information tool/resource/thing you feel would benefit you and other families at The Children's Inn. This is meant to be a discussion so you don't have to raise your hand to speak; this focus group will last for about an hour so feel free to provide a lot of information. Also, say what you think and ask any questions.

*Note to self: 7 minutes of discussion for each question including the introduction

Questions with Categories

Ice-breaker

1. Before we begin, how about we go around the room and introduce ourselves. You can say your name and how long you have been coming to The Children's Inn.

Information Needs

1. Would you tell me about your child's condition?

2. Is there any information you would like to know about your child's condition?

Acquiring information

1. Where do you look for health information?

2. How do you look for such information?

Desire for an information resource

1. Would you want The Children's Inn staff to guide you to consumer health information? If so, why?

Design and usage of the resource

1. If you could create the perfect health information resource (or thing/space), what would it look like and how would it work?

    a. Follow up questions (use if there are few responses)

        i. Are there any health information resources you use often?

        ii. What do you like about them?

2. What are the most important topics and information that should be included in the resource?

3. Who would use it?

Follow-up

Thank you again for participating in the focus group. If you feel that you have more questions or comments that you want to make about the tool, you contact me or one of the other Resident Services staff at The Children's Inn.

Appendix G: Potential Project Proposal for Next Phase of Children's Inn Information Needs Project

Background

The Children's Inn is a hospitality home where seriously ill children and their families stay while participating in medical research at the National Institutes of Health (NIH). The staff at The Children's Inn want to create an information tool that would connect families to credible health resources that meet their information needs.

Objective

A working list (found on an Excel spreadsheet in the Associate Fellow Reports section under Moses, Tyler) of health topics that the families and patients are interested in has been because of an information needs assessment done in Spring 2017. The goal of this project is to take the topics from the list and identify resources the can meet this needs. The order in which resources would be identified are: federal-produced (i.e. NLM, NCI, etc.) resources and credible resources produced by private and/or non-profit agencies. Once all the resources have been detected, the health topics that did not have any corresponding health information sources should be highlighted. If there is remaining time, the intern would work with the staff at The Children's Inn to generate ideas as to what additional resources (i.e. webinars, guides, research consultations, etc.) could be created to meet some of the needs identified from the Spring 2017 needs assessment. Data from this assessment will be available the Associate Fellow Reports section under Moses, Tyler.