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Leveraging Health Informatics and Parental Empowerment: Perspectives from Parents and Caregivers of Medically Complex Children

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Leveraging Health Informatics and Parental Empowerment: Perspectives from Parents
and Caregivers of Medically Complex Children

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Abstract

This research paper focuses on the barriers that parents and caregivers of special-needs children patients face with leveraging technology and informatics as they attempt to communicate with their child’s healthcare specialists regarding specialized and critical oversight and management of complex medical conditions and the need for empowerment for this population of parents and caregivers. The literature suggests that the age and socioeconomic status of the individual has a big impact on the use of electronic applications. A review of the literature showed that the special needs population has not been represented. This study surveys a range of parents and caregivers to include a various age ranges, genders, education and socioeconomic statuses to identify the barriers this unique population has encountered.

Chapter 1: Introduction

Electronic patient portals are becoming a widely acceptable way for patients to access their own health records and information. These electronic health record systems have led to the transformation of education to the average patient. Patients can now take a more active role in their own healthcare because the information is available at their fingertips. With a click of a button a patient is able to message his or her physician or care team and receive updates regarding prescriptions, labs and x-rays, test results, and emails. An informed and highly responsible patient means better health outcomes. For the parents or caregivers of a medically complex child, the help of patient portals enables them access to their clinician’s documentations, thereby leading to a staunch patient-centered as well as a family-centered healthcare approach (Ammenwerth et al., 2012).

Table of Terms and Definitions

Term	Definition
Medically Complex Child	A child who has high health care needs or health services utilization with multiple, significant chronic health problems that affect multiple organ systems and result in functional limitations (American Academy of Pediatrics)
Complementary Therapy	Therapeutic techniques which are not considered to be standard or established medicine practices or treatment. When a non-mainstream practice is used together with conventional medicine, it’s considered complementary (John Hopkins Medicine)
Conventional Therapy	Therapy that is widely used and accepted by most Health professions (John Hopkins Medicine)

Background

Telemedicine and Telehealth applications are proven very successful in terms of providing special and extra care for patients of all age groups and for patients with acute or chronic conditions. Healthcare professionals, specialists, and other members of the interdisciplinary team were highly satisfied by remote setup programs offered to patients and families (Hooshmand & Yao, 2017). Individuals and families in rural geographical areas are one of the greatest consumers of the telehealth, telemedicine, or other remote applications. These technologies overcome the barriers of long route travelling, looking for subspecialty physicians and tertiary health care providers, managing and requesting time off from work, and relying on emergency department services or over the counter medications for temporary measures (Marcin et al., 2004). There is no doubt that traditional way of assessing and evaluating the patient face-to-face is a priority among many patients and healthcare providers. However, if we compare health informatics applications such as telehealth, telemedicine, remote monitoring, and “store and go” technology with face to face visits, then it has been found that majority of the end consumers were highly satisfied with the remote management of their care whereas the health care providers were equally satisfied with the quality of assessment they provided from afar (McConnochie et al., 2015).

However, the current state of advocacy for health informatics applications is leaving the most vulnerable patients behind. In many healthcare systems, patients can access health informatics applications that allow them to manage and coordinate their child’s care. For a parent or caregiver of a special needs or medically complex child, access to these technologies is an obstacle. Firstly, if the special needs or medically

complex child is uncooperative, getting the child to sit in front of the camera for a telehealth/telemedicine or remote visit is nearly impossible. A physician cannot treat the patient if he or she cannot “see” the patient. Parents and caregivers do not receive the same feedback or body language clues that are seen in a face to face encounter.

Therefore, it is difficult for a parent or caregiver to feel confident that the healthcare provider is paying attention and capturing the essential exchange of information as the parent is trying to contain the child. There is also no guarantee of patient confidentiality that is offered by the simple closed door of doctor’s medical exam room. Secondly, online applications such as patient portals are generally available in English—or in a best-case scenario—English and Spanish. Parents of special needs or medically complex children may have limited English proficiency or low health literacy which becomes an obstacle to leveraging this technology. Thirdly, before a parent can discuss his or her child’s medical and health needs, a cumbersome on-boarding process must be completed to confirm a patient’s identity which can include verification of legal documents for guardianship or conservatorship.

This research paper will review the critical role that telehealth/telemedicine, online patient portals, and other health informatics applications play in helping the parents of special-needs children leverage technology in the care and treatment of their child with complex medical conditions. Barriers to parental empowerment and effective communication between healthcare providers and parents/caregivers of special needs children will also be identified and examined.

Purpose of Study

This study set out to identify the barriers that parents and caregivers of special needs and medically complex children face when communicating with healthcare professionals, accessing and using applications and technology, leveraging electronic information, and advocating for a holistic family approach to healthcare which can benefit their special needs or medically complex child. The literature shows that although parents and caregivers of special needs children have not been represented, this population can gain the biggest benefit (Burke, 2015). It is critical to understand why this patient population is not represented. Once the barriers are identified, solutions can be provided to offset these barriers and improve the use of informatics to advocate and manage the care of special needs and medically complex children by their parents and caregivers.

Significance of Study

The world is evolving exponentially and at a rapid pace. The field of healthcare is transitioning quickly to keep up pace with technological changes. Healthcare is an area of great scrutiny for healthcare professionals, politicians, and the general public. The advancement in telecom technologies has changed the way we communicate with each other and, hence, has helped to create and evolve a 'global village'. If available technologies are not being used by parents and caregivers of special needs and medically complex children, this can result in gaps in care and treatment for patients who are unable to make medical decisions for themselves. This patient population can gain much benefit from parents and caregivers who are educated about leveraging existing technologies which can lead to better health outcomes for the patient as well as the entire family. The

barriers to communicating with healthcare providers and leveraging existing technologies should be identified so that inefficiencies and gaps can be identified and addressed. This study can help to identify how to empower parents and caregivers to eliminate communication barriers and leverage existing technologies and informatics.

Research Questions

- Are advancing technologies and strategies helping to empower parents of a unique patient group to reduce or eliminate barriers to quality care?
- What is the importance of utilizing health informatics from the perspective of a parent who has a medically complex child?

Demographic Questions

1. What is your age?
2. What is your race?
3. What is the size of your family?
4. What is your education level?
5. What is your income level?

Limitations

This survey was administered to a group of parents and caregivers of special needs and medically complex children in an online forum. Since access to this closed group/online forum is restricted to members only, a part of the population may not be represented. This may lead to parents and caregivers who are internet-savvy responding to the questionnaire and they tend to be a younger demographic. Time and money do not permit an in-depth interview with each patient, so a questionnaire was used to access the information. The questionnaire was created in a multiple-choice or short answer format

that led the patient to choose an answer presented on the form even when their choice was not on the list. Patients may not have understood each of the questions or understood how a question may pertain to their child's medical condition. There is a possibility of selection bias in which patients that are familiar and comfortable with apps, technologies, and informatics may have responded more than persons who were unfamiliar with, or resist, technology and informatics. Participants that prefer written, paper questionnaires rather than digital or online technology may not have participated.

Chapter 2: Review of the Literature

A literature review was performed to identify the research that has already been completed about leveraging technology and informatics and parental empowerment in the care of medically complex children. Healthcare professionals have begun to place emphasis on ensuring that healthcare services to children with special needs are family-centered (Dempsey and Keen, 2008). The inclusion of the parents and any siblings in the holistic approach to caring for complex needs of a special-needs child strengthens the parental roles with healthcare professionals (Lindblad, Rasmussen, and Sandman, 2005). Barriers to parental empowerment and utilizing the applications and technologies as caregivers to medically complex children was also researched in the literature review. Parents of medically complex children often feel that they face challenges in accessing their child's information (Wodehouse and McGill, 2009) and that healthcare professionals may not view the parents as the subject matter experts of their medically complex children (Lundeby and Tøssebro, 2008).

Materials and Methods

Identification of articles. A literature review was performed using PubMed, US National Library of Medicine National Institutes of Health, Google Scholar search engine, and industry websites such as CMS, AMA, CDC, and online medical journals.

The research was conducted using combinations of key terms: health informatics, health information, parental rights, medical conservatorship, patient, parent, special needs, disability, chronic, medical, telehealth, telemedicine, and patient rights. Searches were also performed specific to electronic health record, personal health record, and portal.

Inclusion and exclusion criteria. The literature review and research was limited to studies performed and completed in the years 2000 through 2020 to capture the most current information. Studies and research performed outside of the United States were also included in this review because technologies and access to, and communication via, online patient information is universal. Healthcare providers and patients face similar benefits and challenges. The articles reviewed for this project are from primary sources that focus on leveraging health informatics and empowering caregivers as well as a patient-centered approach to healthcare

Literature Review Process

The initial search in PubMed produced 48 articles. The initial search in US National Library of Medicine National Institutes of Health produced 61 articles. And, an online Google Scholar search produced 36 articles. All of the articles retrieved were reviewed for duplicate information and any irrelevant information. Exclusion of the duplicate and irrelevant articles yielded a final number of 40 articles that remained. After

a second, thorough review of the 40 articles, 5 articles were excluded for reasons of date out of range, irrelevant information, or duplicate information. This resulted in 35 articles included in the review.

Findings

Utilizing health technologies can be scary and burdensome for some individuals. Typically, the challenges to utilizing health informatics applications such as online patient portals, telehealth and telemedicine are slow to be accepted by patients who have been conditioned to physically travelling to their healthcare provider's office in order to receive treatment, and who may be hesitant to learn how to use electronic media to share personal medical information. However, after careful review of the literature, it was identified that the use and acceptance of health informatics applications is by a wide range of individuals, regardless of the age, race, education, or economic status (Cameron, 2018).

The literature review included studies on all various patient demographics. Most of the articles focused on the benefits and streamlined processes that have been developed to ensure accurate exchange of information electronically between healthcare providers and the caregivers of medically complex children. Focused questions during visits improved communication between provider and parent of medically complex children (Berman, A. C., & Chutka, D. S. (2016). Additionally, a review of a study focused on the benefits of telehealth applications for medically complex children and their families (Hooshmand, M., & Yao, K. (2017), and benefits to the exchange of information with parents (Orlando, J. F., Beard, M., & Kumar, S., 2019). Another study

cited greater ease of access to medical information for parents and caregivers, flexibility in scheduling around a medically complex child's schedule, and affordable cost as benefits of telehealth (McConnochie et al. 2015).

It is evident through the review of literature that the introduction of new technologies in medical field requires end-user and consumer satisfaction and acceptability at the same time (Pathipati, A. S., Azad, T. D., & Jethwani, K., (2016). Orlando, Beard, & Kumar (2019) discussed that in order to determine the feasibility of the newly introduced technology and prove its favorability patients must be educated and made to feel comfortable with health informatics applications and technologies. Health information technology (HIT) has evolved with a number of applications that have facilitated the medical delivery by the healthcare professionals (Ammenwerth, E., Schnell-Inderst, P., & Hoerbst, A., 2012). These applications include the telehealth/telemedicine, online patient portals, and direct email messaging to physicians. The literature identifies many benefits to the patient and patient's family with the integration of healthcare and technology. Ease of access, flexibility, and affordable cost are all factors associated with the acceptance of health informatics applications (von Thiele, 2016). The rise of telehealth and telemedicine and its integration into communities and society has eradicated geographic, cultural, or ethnic barriers in the application of healthcare delivery (Marcin et al., 2004). As a result of this invention, medical facilities have transferred from big tertiary healthcare buildings to homes, community based health programs, audio or video calls and even online chat sessions (Orlando et al., 2019).

The literature pointed to some challenges with utilizing health informatics applications outlined (i.e. telehealth/telemedicine, online patient portals, and direct email messaging to physicians) which included lack of ethical and privacy concerns with respect to the patient's data (Sunyaev et al., 2015). As healthcare providers use 'store and forward' technology most of the time—which means that the patient's past medical history, presenting medical complain, diagnostic imaging and other crucial insurance data is stored within a third-party system—the information is housed and sits in a portal. This has led to an increased fear of the data being accessed by unauthorized users and hacked anytime (Berwick & Gaines, 2018).

Cameron's (2018) article, "Barriers to Parental Empowerment in the Context of Multidisciplinary Collaboration on Behalf of Preschool Children with Disabilities" was reviewed as part of the research process for this project. This study was very central to the research completed for this project. The purpose of this study was to explore the role of parents in "*multidisciplinary collaboration on behalf of their preschool-aged children with disabilities from the theoretical perspective of empowerment. The study employed a multiple-case study design, including twenty-six individual and two focus group interviews with parents and professionals supporting six children and their families. Three interconnected themes emerged from the analysis. First, parents struggled with navigating a system that was perceived as rigid and cumbersome. Second, parents often found themselves in the position of having to 'police' the professionals involved in supporting them. Third, parents expressed a desire to 'just be parents' and relinquish a degree of control to professionals. Findings highlight central dilemmas associated with*

the goal and process of empowerment in the provision of social, educational, and health-related support” (Cameron, 2018).

Limitations

Each article or study had a different approach or focus as it related to leveraging available technologies and tools and resources that were identified to be used by parents and caregivers of medically complex children as well as potential barriers to availing these technologies. Disjointed care coordination is a potential barrier (Barry, M. J., & Edgman-Levitan, S., 2012) while other barriers include difficulty in accessing a family members medical information (Berwick, D. M., & Gaines, M. E., 2018) and limited inclusion of family-centered approach (Hill, C., Knafl, K. A., & Santacroce, S. J., 2017). The articles did not outline or specify age ranges of medically complex children or parents. Nor did the articles define the age of the patient when his or her parent or caregiver adopted health informatics technologies.

This study was small and did not include a diverse sample of the general population. It is believed that many potential participants are still represented within this small study sample as informal discussions regarding the oversight and coordination of care for a special needs or medically complex child within a close, private parents group were mirrored in the responses that were received through the formal questionnaire survey.

Many participants did not have higher education. This can be attributed to the extreme and exhaustive nature of caring for a special needs or medically complex child.

This can also be attributed, in part to, most participants being the sole caretaker or raising their child as a single parent and not having the financial means to pursue an education

Conclusion

This literature shows that the benefits for a parent or caregiver in leveraging health informatics in the care and treatment of a medically complex child is attributed to the use of available technologies to eliminate access, communication, and cost barriers to quality healthcare, and the reduction of gaps in information and documentation critical to promoting an environment that empowered parents and caregivers. In a family-centered approach, parents are recognized as the most significant and influential people in the child's life (Rouse 2012). Although barriers do exist and can cause potential challenges to end users, the parent or caregiver must be given education and insight into how health informatics can help to facilitate quality care for their special needs or medically complex child while relieving some of the burden on the parent or caregiver to be the gatekeeper, recordkeeper, and paperwork coordinator. In this manner—when healthcare professionals and parents share tasks and goals that are of direct benefit to the child—the parental role is strengthened.

Chapter 3: Methodology

The methods used to recruit participants and collect data for this study included an online survey posted to a closed Facebook group called “Parents of Special Needs Children”. This group was selected to administer the questionnaire as this demographic is key to understanding the challenges and barriers that parents and caregivers of medically complex children face when attempting to avail new technologies to help their child

receive quality healthcare services. Every single participant is the parent or primary caregiver to a medically complex child under the age of 21 years old.

Research Design

The research design utilized structured questions in an online questionnaire format. The questionnaire was created and made available to members of a closed Facebook group that was created and designed to share information, tools, connections, and resources for parents of special-needs children. A literature or study search did not result in a prefabricated survey or questionnaire that would be applicable to this research project, therefore, a questionnaire was created. A simple random sampling method was used.

Population and Sample Design

A questionnaire was created in order to obtain anonymous data from individuals of the population as a whole. A sample within a specific population that represents individuals from varying demographics such as age, gender, education, and socioeconomic status was desired.

Data Collection Procedures

A mix of closed and open-ended questionnaire (Appendix B) was designed and published to a closed Facebook group created for parents of special needs children. The closed, private Facebook group was created in 2014 and currently has 7,799 members as of the date of this paper. The Administrators of this group were approached with a written request to allow a research questionnaire to be posted. This group has 536 active

members. The questionnaire was posted on February 3rd, 2020. The questionnaire was active until April 29th, 2020 to allow for participant responses.

Data Collection Instrument

The instrument chosen for this research project was a questionnaire (Appendix B) that was made available to parents and caregivers of special needs and medically complex children that belong to a closed, private Facebook group. The online questionnaire included a cover sheet (Appendix A) which requested participants to identify family demographics.

Summary of Chapter 3

A random sample of the population was obtained after publishing the questionnaire to a closed, private Facebook group of parents and caregivers of special needs and medically complex children. Results were quantified and analyzed based on identified technological and interpersonal barriers, age, gender, socioeconomic status and education level.

Chapter 4: Results

The data from the online questionnaires were analyzed. The end results were grouped and compared. The different groupings included: identified technological and interpersonal barriers, age, gender, income level and education level.

Response Rate of Population

Nineteen parents/caregivers from the closed, private Facebook group “Parents of Special Needs Children” participated in the completion of the questionnaire. A reminder was sent out to the group after 3 weeks to ensure enough parents/caregivers participated. The survey resulted in a response rate of 0.04%.

Profile of Population

After evaluation, the general profile of participants was found to be single, stay at home mothers with incomes levels below \$50,000 per year. As women tend to be the primary caregivers in most societies, the questionnaire respondents were predominately female. The age range of the participants was between 20 to 50 years old with a mean age in the range of 32-37 years of age.

The participant demographic information for this research project is as follows:

- All 19 respondents were Female

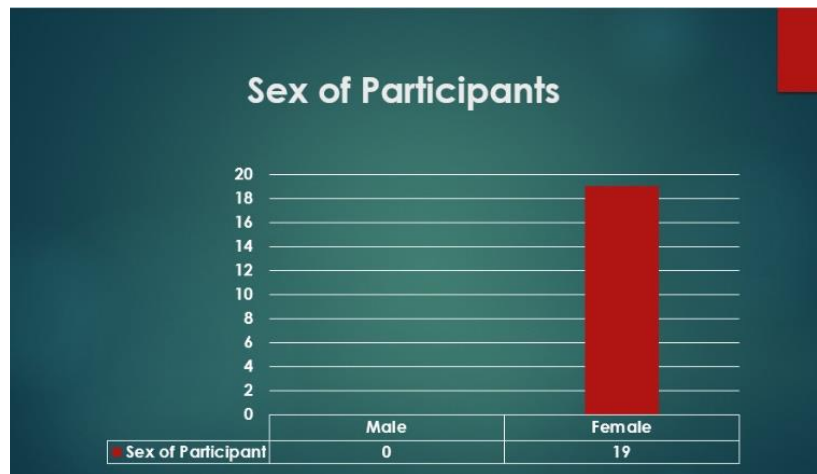


Figure 1: Participant's Sex



Figure 2: Age Distribution of Participants



Figure 3: Income Distribution of Participants

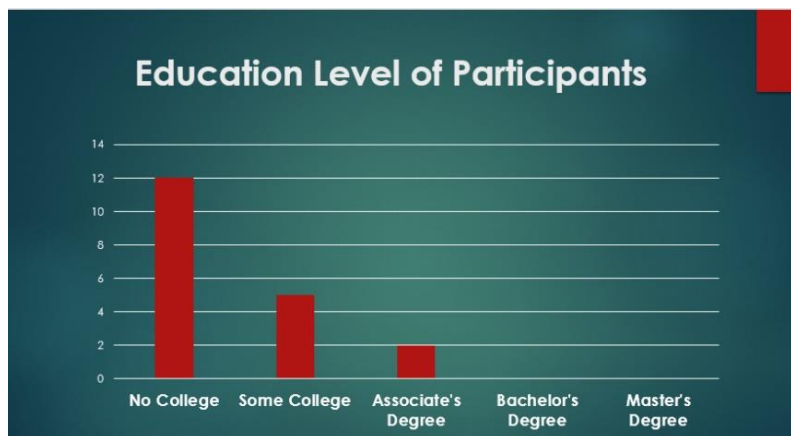


Figure 4: Education level of Participants

Results of Research Questions

Question #1

1. What are the 3 main concerns you have with sharing medical information about your medically complex child FACE TO FACE with a healthcare provider/specialist?

Responses:

- Lack of interaction with physician (physician busy typing or acts like he/she not listening)
- Time constraints (office appointments are scheduled in 15- or 30-minute increments which is not sufficient for special needs patients)
- Embarrassment, anxiety, not being taken seriously and as an expert regarding my child

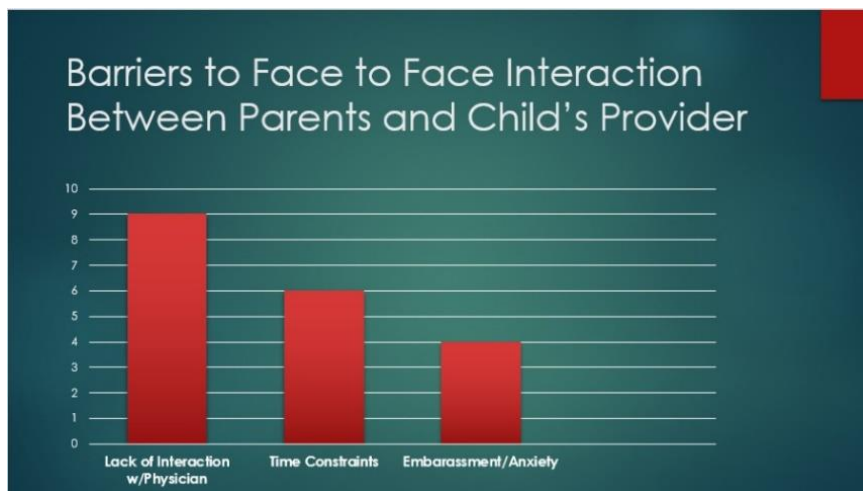


Figure 5: Barriers to Face to Face Interaction

Question #2

2. What are the 3 main concerns you have with sharing medical information about your medically complex child ELECTRONICALLY with a healthcare provider/specialist?

Responses:

- IF the information about my child is safe and secure
- IF the physician actually looks/reads the info or delegates to someone else
- Information may be stored in different parts of the EHR and maybe physician doesn't even see/read it

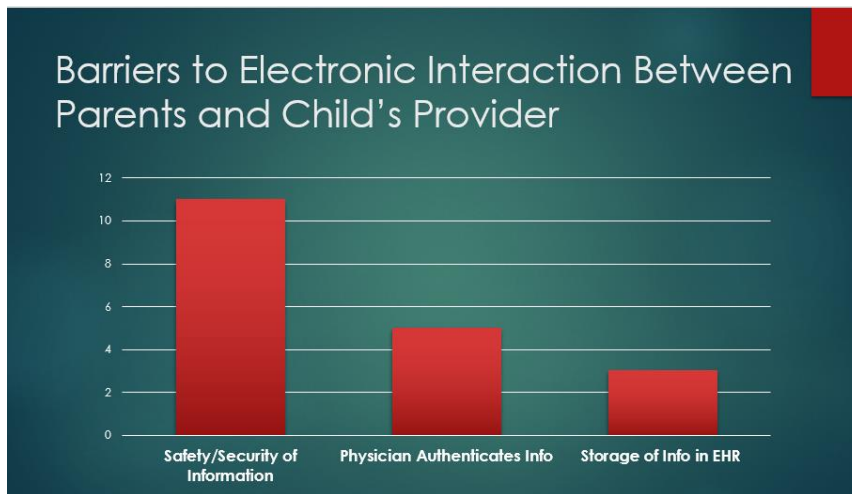


Figure 6: Barriers to Electronic Interaction

Question #3:

3. What communication barriers have you experienced with your child's healthcare provider/specialist?

Responses:

- Lack of timely responses to messages/emails
- Lack of privacy
- Online/electronic portals not easy to access/maneuver for our children

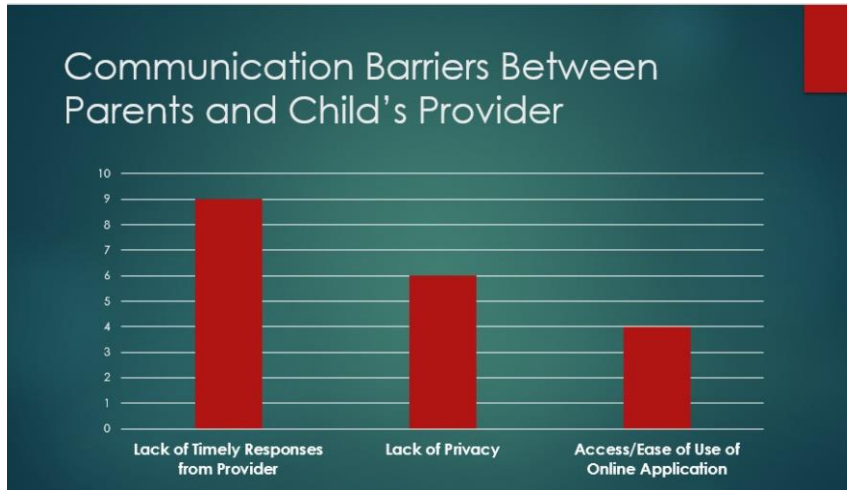


Figure 7: Communication Barriers

Question #4:

4. What technological barriers have you experienced when you communicated with your child's healthcare provider/specialist?

Responses:

- Online/electronic healthcare portal setup for minor/adult child extremely difficult and requires legal justification (i.e. conservatorship/guardianship)
- Healthcare provider/specialist does not advocate or help with understanding how to effectively utilize and communicate through EHR/PHR/Online Portals for parents and caretakers
- Flow of information and communication between healthcare providers and parents of special needs children is fragmented and disjointed

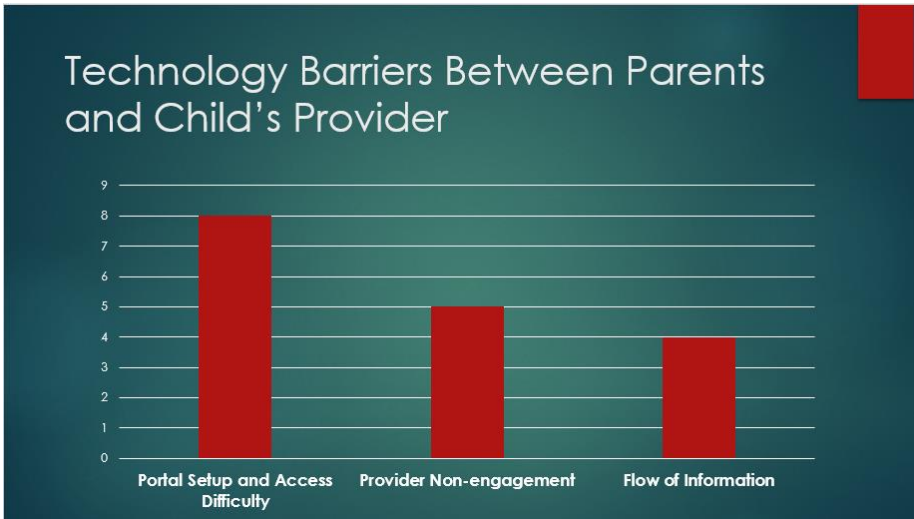


Figure 8: Technology Barriers

Question #5:

5. Do you feel that healthcare providers/specialists include you –as the parent/primary caregiver—in every level of the decision-making process?

Responses:

- Total of 19 responses
- 7 participants replied YES.
- 12 participants replied NO.

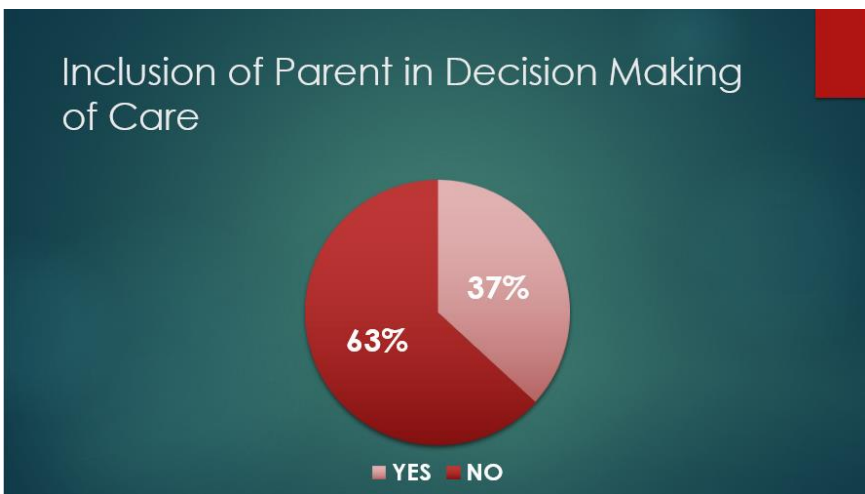


Figure 9: Decision Making of Care

Question #6:

6. What strategies have you used to overcome barriers to effective communication with your child’s healthcare provider/specialist?

Responses:

- Extensive preparation for all doctor appointments (providing written documentation such as IEPs, school medical forms, etc.)
- Utilizing telehealth appointments (i.e. if child is not cooperating or feeling well and appointment would be cancelled, with telehealth the appointment can still occur and patient receives care and treatment that would have otherwise been cancelled).
- Avoid negative questions. Focus on solutions and alternatives in treatments.

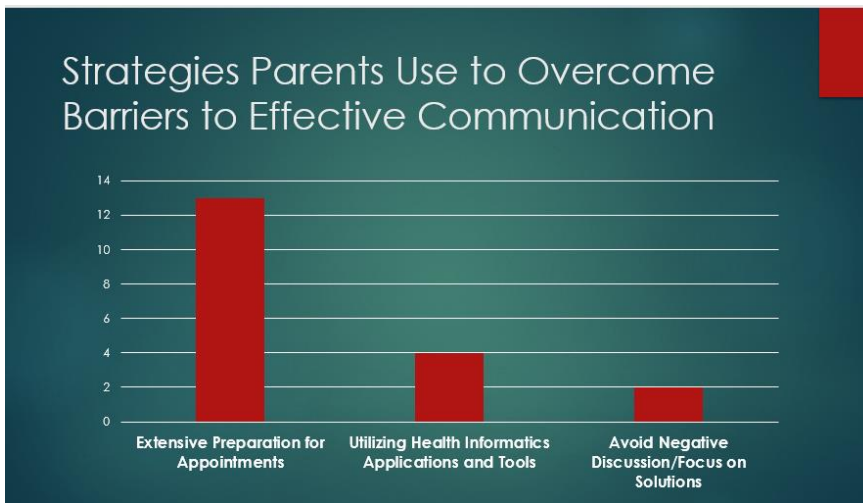


Figure 10: Strategies to Overcome Communication Barriers

Question #7:

7. What are some ways that you ensure your medically complex child’s medical record/information is accurate and up to date?

Responses:

- Detailed record-keeping by parents and caretakers (the hefty work required to meet the needs—multiple phone calls, faxes, and emails; paragraphs and pages of documentation and forms)
- Updating, maintaining, and sharing medication, allergy, emergency protocol lists
- Utilizing personal health record apps and portals

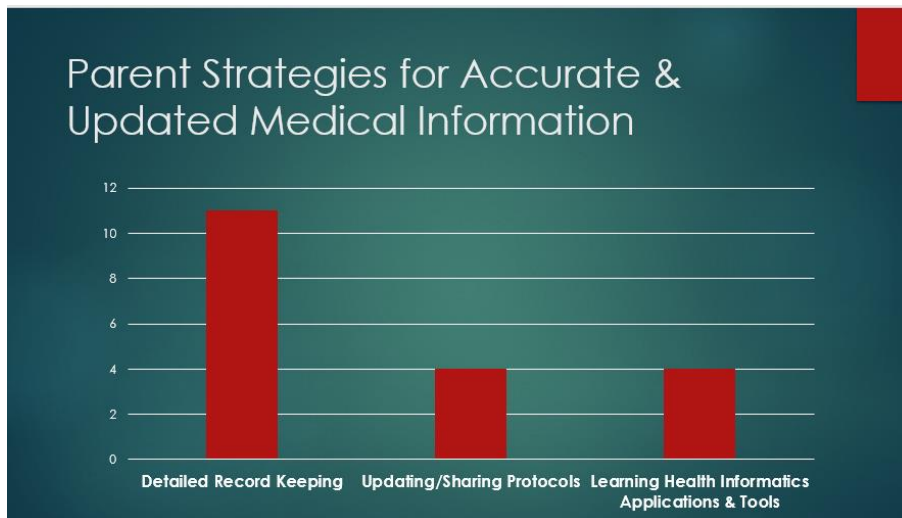


Figure 11: Strategies for Accurate & Updated Info

Question #8:

8. How easy is it for you to access & manage your medically complex child's health information?

Responses:

- Very easy
- Somewhat easy
- Difficult
- Extremely difficult

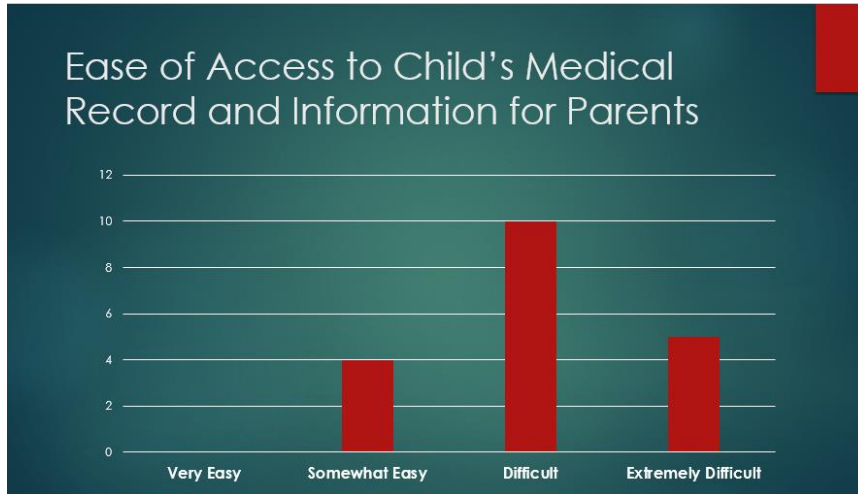


Figure 12: Ease of Access

Question #9:

9. A “family-centered” approach to healthcare means that the strengths and needs of all family members are considered when treating a patient. Do you feel a “family-centered” approach to healthcare for your medically complex child(ren) is beneficial?

Responses:

- Total of 19 responses
- 15 participants replied YES.
- 4 participants replied NO

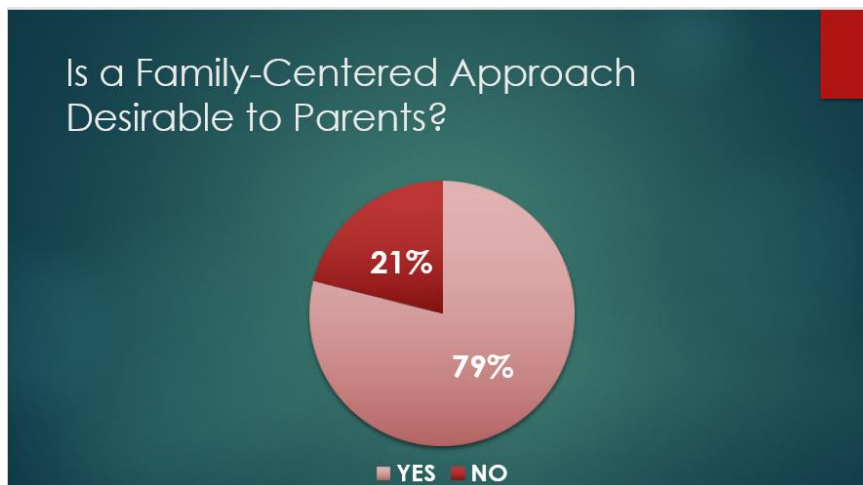


Figure 13: Usefulness of Patient Centered Approach

- How would this affect your medically complex child and family?
 - Reduce anxiety of all family members; help with “care planning”
 - The entire family would be generally healthier
 - Avoid Strengthens the bonds between the family/siblings/caretakers of special needs child and other family members; improves family dynamic

Question #10:

10. Information technologies can empower parents of medically complex children by providing a mechanism for interaction with physicians and the healthcare system. Have healthcare providers/specialists encouraged you in the use of evolving information technologies for information exchange?

Responses:

- Total of 19 responses
- 6 participants replied YES.
- 13 participants replied NO

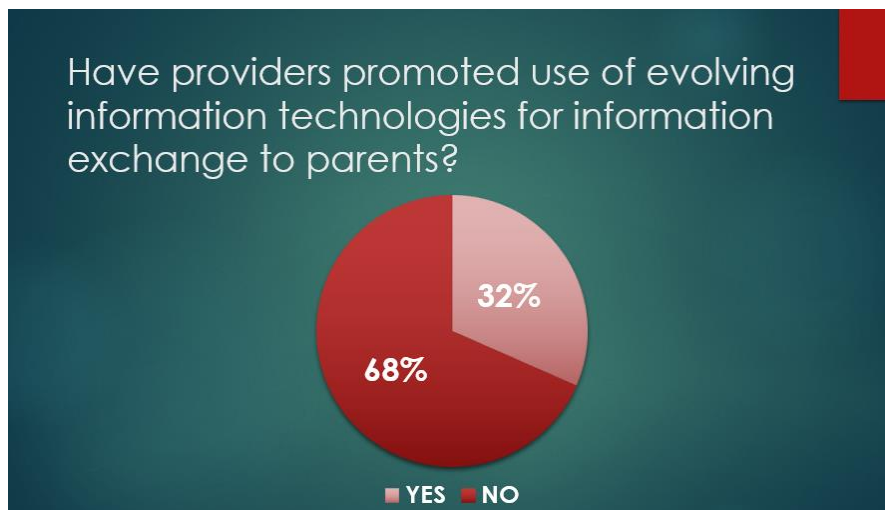


Figure 14: Promotion of Technology by Providers

Summary of Chapter 4

Results were analyzed to identify and compare the participants responses to each of the research questions on the questionnaire. The participants age, gender, income levels and education were evaluated and reported. This research project identified that the general profile of a participant was a female with a mean age range of 32-37 years old, lives in a single-parent household, has limited education, and earns an income below \$50,000 per year.

The average participant has experienced difficulties in communicating with her child's healthcare provider, and with accessing and utilizing health informatics applications such as telehealth/telemedicine, online portals. She has had difficulty in expressing her subject matter expertise with healthcare professionals and struggles to keep documentation updated and communicated/exchanged with her special needs child's healthcare providers and specialists. She also believes that a patient-centered approach to healthcare would be beneficial to her special needs child and her family as a whole but may not have had this discussed with her by the healthcare provider.

Chapter 5: Conclusions and Recommendations

Summary of Findings

Concerns with Sharing Information in Face to Face Interactions

One of the main concerns of parents regarding sharing confidential medical information of their medically complex children with their physician is lack of communication. They complain that doctors do not listen to them when they are talking or explaining their and their children's situation (Berman & Chutka, 2016). Lack of communication skills in physicians and improvement in the respective room has been a

constant concern since the dawn of medical era. Empathizing with their patients at an emotional and humane level is very much required to be practiced in medical profession. But unfortunately, instead of normalizing this trait of medical professionals, it has become one of the greatest concerns of patients. Parents, who are already agitated and distressed by the condition of their children, complain that the doctors only “act” like they are listening to them but in reality, they are busy on their computer work or rambling throughout the conversation. This eventually leads to mistrust and increased anxiety in the parents.

A detailed medical history is imperative to an accurate diagnosis as 70-80% of the treatment depends on the elaborate medical history of the patient. As the parents of disabled and medically complex children, parents and caregivers find it difficult to explain their concerns and difficulties to their child’s physician in the constrained consultation time. They find it apprehensive when the physician only has 10 to 15 minutes to spare in order to evaluate their child. They prefer “complementary” therapies as opposed to conventional therapies. Majority of the physicians rely on bookish knowledge and evidence-based practice but forget about the human nature of the profession. Healthcare workers who make eye contact and connect with patients and parents/caregivers and spare enough time to listen to the patients in detail, allow their patients to feel valued and listened to (Robertson, 2017) as empathy and good communication skills have been linked to higher parent’s satisfaction and improved health outcomes (Berman & Chutka, 2016). Since the examination of a medically complex child requires time more than an adult patient, parents look up for physicians

who examines their child thoroughly, communicate and understand not only the parent's situation but also the child's condition as well.

Another main concern of parents regarding their physician's appointment with their medically complex child is the feeling of embarrassment and anxiousness when dealing with them face to face. They feel that their opinion would not be taken seriously by the healthcare provider. Physicians who do not provide eye contact to their patients and proper attention to the parents leave them with embarrassment and feeling of anxiety (Robertson, 2017). Studies have shown that about 50% of the physician's time is spent on computer while examining his patient in the examination room (Gawande, 2018). This leaves the already anxious parents in a state of discountenance feeling an inferiority complex that the doctor doesn't take them seriously regarding the condition of their own child. A discomforted parent will eventually have less faith in the doctor, therefore, decreasing the probability of a better health outcome of their children in the end.

Concerns with Sharing Information in Electronic Interactions

The second question of the questionnaire was the concern that parents have when they state the problems regarding their medically complex child to their physician via a telecommunication device. The very first and major concern was regarding the security and the ethical concernment of the child's medical information. The medical information stored and delivered via an electronic device always leaves a speculation in the minds of the parents related to the secured perseverance of the confidential information of their child's health. The electronic media uses various technologies in the medical field one which is "store and forward" technology which means the private data of the patient is

stored in a third-party interface which increases the chances of misinformation or sabotaged data delivered to the physician.

Parents—while using the technologies in order to deliver medical information of their children to the doctor—are worried about whether the information that is shared would actually be delivered to the respective physician or would go unnoticed, undocumented, or shared with some other personnel. Patient's authentication and preserving obscurity is also one of the main concerns when using telemedicine (Miller et al., 2020). This can generate a confusion regarding the respective patient's data (Ginige & Maeder, 2018).

The world of medicine is expanding its branches into the technological advancements with its own pros and cons. Health informatics has introduced different interfaces that have eased the daily work of healthcare professionals. Health Informatics applications such as the Electronic Health Record (EHR), telemedicine and telehealth, remote monitoring, electronic patient portals etc. come with cons or challenging aspects that have caused patients and their parents much concerned. Workflow problems, communication problems, technical problems and consumer-related problems are some of the issues that comes with the operation of electronic healthcare systems (Vanderhook & Abraham, 2017). Healthcare professionals are trained to operate these newly introduced systems and work to maintain the workflow and appropriateness of the medical data. However, parents of the medically complex children may not have much knowledge related to these systems. Therefore, they are unaware of how to properly update and maintain any required information into the system. This is the reason why parents are anxious and confused related to the use of such advanced technologies.

Because parents and caregivers are unsure and cannot confirm whether the medical information of their child is delivered and seen by the respective physician or another healthcare professional such as medical assistant or nurse practitioner, they are less likely to exchange information through the health informatics applications.

Health informatics has opened gateways to many essential technologies. But public awareness and education and a focused outreach to special needs families is critical. Technology should aid in the coordination of healthcare services for medically vulnerable individuals to ensure health equity.

Communication Barriers

When parents or caregivers of critically ill children decide to use informatics applications for the transfer of medical data to their healthcare provider, obstacles like communication barriers can arise. Difficulties such as network and technological inconsistencies, lack of body language and trust, lack of high-end telecom services, scheduling conflicts, technological hindrances and cultural barriers are just a few examples. There might be technical difficulties in the network system for either one or both ends users. These examples of communication barriers point to areas of concern for parents and caregivers. In addition to these barriers, there are other concerns faced by the parents of medically complex children that are related to the use of telecom systems in seeking medical care (Marcin et al., 2004) such as lack of education or enough knowledge related to the technology, network availability, privacy, legal issues etc.

When the sample population was asked about the different communication barriers they face when dealing with their child's healthcare provider, the barrier that topped the list was the untimely response by the physician. Parents complain that they

wait for days and weeks just for the response of the consultation they require by the doctors. There are many reasons why such barriers can hinder the smooth flow of medical care deliverance such as lack of time at the physician's end, network issues, busy schedule and overburdened applications. A physician might not be able to attend to phone calls, text messages or emails due to a number of reasons. However, the uncertainty of whether or not the healthcare provider has received, seen, or read the communication is frustrating for parents and caregivers.

According to the results from the questionnaire, privacy issues regarding the sharing of medical information of their children was the second most common concerns for the parents. As the doctors use “store and forward” technology, which means the incoming data is stored in a third party interface for evaluation and then sent to the doctor, this creates sense of vulnerability in the minds of already anxious parents as there are rising concerns related to the privacy and intimacy of confidential patient information (Vyborny, 1996). Sharing such sensitive and crucial information with someone is already a tough task—both emotionally and mentally. But, when parents and caregivers must also worry about the safety, security, and confidentiality of an electronic message exchange, this puts parents on edge and does not promote parental empowerment.

The implementation and use of health informatics has helped to streamline the exchange of electronic information and documentation for healthcare provider (Marcin, et al., 2014). However, at the same time, these newly introduced technologies are difficult to understand and utilize for some parents. Healthcare organizations work with Information Technology departments to arrange various workshops in order to train the healthcare providers and doctors in the use of these technologies. But there are no

workshops arranged for the parents and caregivers of medically complex children.

Therefore, this is an area of main concern among this population while using electronic means for seeking medical care (Vanderhook & Abraham, 2017).

Technological Barriers

Electronic media/medical delivery systems have proven to be very effective and handy when dealing with remote health care delivery. Telemedicine has proven to be effectual in the pediatric cases as tele-consultation has made health care delivery very much accessible to parents of young children (Burke et al., 2015). However, one of the main technical barriers faced by the parents was the legal justifications and technological set-ups for the young adult or minor children. As telemedicine and other forms of health care informatics eases the access of health care facilities, parents rely on such technologies for their child's care while they carry on with their own tasks and daily routines of the child. But these technologies require the legal conservatorships and guardianships in order for parents and caregivers to access them. Hence, parents found it difficult to setup appropriate proxy accounts in order to have control over their child's medical health record and coordination of care, working tirelessly to legally authenticate the use of health care informatics for their children's medical information.

Fragmented and disrupted flow of information between the clinicians and the parent of the medically ill children is also a significant barrier while using any form of healthcare informatics. When a parent or a guardian uploads any medical data on an electronic portal or forum, that data is not only stored and processed in the clinician's EHR system but also on the hospital's EHR and national health data registries (Smaradottir & Fensli, 2019). This leads to either delay in response from the healthcare

team or results in fragmented flow of informational response between doctor and parent or caregiver of the special needs or medically complex child. Parents may have to wait in the “virtual” waiting rooms or online queues with long wait times.

Inclusion in Decision Making Process

Patient centered as well as family approach is essential to effectual healthcare delivery (Barry & Edgman-Levitan, 2012). As much as it is emphasized upon in the literature, it is not at all being implemented practically. When the parents of special needs or medically complex children were asked about their involvement by clinicians in the clinical decision making of their child’s health, the majority of the responses that were recorded were negative. Most of the parents felt left out of the process when important decisions were made regarding their child’s health. Under-aged and young children are unable to make medical decisions for themselves and so parents and caregivers must make advocate for the child—especially when that decision is not fully supported by a healthcare provider.

Family centered approach to medicine has been used for the past 40 years (Bamm & Rosenbaum, 2008). The importance of this concept is emphasized in the area of pediatric healthcare delivery. Collaboration of parents and healthcare professionals is necessary for better healthcare treatment and delivery as children cannot advocate for themselves. According to a study that was conducted few years ago, half of the parents of critically ill children were satisfied with the concept of Family Centered Concept (FCC) (Hill et al., 2017). Parents and caregivers of special needs and medically complex children find themselves working to perform their own research and treatment options for their child. This takes time away from the family and other family members. A family-

centered approach to healthcare means that the entire family is considered when developing and administering therapies and treatment for a patient to ensure that every family member's mental and physical health is also considered.

According to the Institute for Patient- and Family-Centered Care's (IPFCC) the four core concepts that are the basis of family-centered care (FCC) are: respect and dignity, information sharing, participation, and collaboration (Hill et al., 2017). Empathy and good communication skills are critical components of a family-centered approach. But parents looking after their children in a pediatric ICU reported inappropriate, coldhearted and adamant behavior from the healthcare providers that lacked compassion and empathy. Sharing children's current health status with their family members in easy and comprehensive language is also considered to be an important building block of a family-centered approach to healthcare.

Collaboration between the parents and healthcare delivery team that takes consideration of each family member and their needs is one of the key elements to promoting a family centric approach in healthcare delivery.

Strategies to Overcome Communication Barriers

Effective communication between the doctor and the patient is of extreme importance in order to achieve optimal healthcare delivery. When doctors effectively communicate with their patients, they gain the trust of their patients and patients tend to follow the advice and recommendations of someone they trust.

The questionnaire included a question for the parents about sharing different strategies that they use in order to overcome communication barriers. The top strategy used by parents in this study was the extensive collection of all of the useful information

related to the medical condition of their child. By being prepared before the medical appointment, parents and caregivers felt they could communicate better with healthcare providers. For this purpose, parents and caregivers prepare the necessary notes and documentation such as their children's detailed medical history, lab reports, imaging reports, any side effects of medications or allergies. That way, when the provider asks probing questions, parents and caregivers could provide the information without bias or difficulties in recollecting details which may be critical for a diagnosis or treatment.

Individualized Education Program (IEP) is a legalized document in schools that contains all of the necessary medical information for a special needs child. It is compiled with the help of the parents themselves and the child's primary care physician who is familiar with the child's medical condition or conditions. Parents are supposed to get detailed copy of this document every time it is updated so that they can provide it to healthcare providers and specialists whenever needed (Hill et al., 2017).

The last but most important solution to the communication barriers between the parents of medically complex children and their parents is the focused state of mind on the solution to the presenting problem rather than outlining just the problems (Berman & Chutka, 2016). This is a very effective way of optimistic approach towards the better future of their children (von Thiele Schwarz, 2016). This approach not only saves time for both parents/caregivers and healthcare providers, but also puts everyone on the same page when it comes to the care and treatment of the special needs or medically complex child. When everyone is on the same page, this creates a positive environment where everyone shares a common goal. Parents of medically complex children can suffer from depression and anxiety (Cohn et al., 2020). With an entire healthcare team of

professionals who are perceived to be on the same page as the parent or caregiver, this creates a sense of empowerment for the parent or caregiver.

Accurate and Up to Date Medical Information

Throughout the survey, the intent was to identify different problems and obstacles that parents face when trying to obtain optimal care for their medically complex child. The questionnaire intends to classify the solutions that parents utilize to ensure a smooth flow of health care delivery for their special needs and medically complex child while also looking at various ways through which parents organize their child's medical data so that they are up-to-date and get accurate medical information. These steps make it easier for the parent as well as the physicians to get all of the detailed medical history that can be otherwise lost or overlooked when primary care physicians or specialists are changed. Being a parent or caregiver of a special needs or medically complex child is a full-time job in itself. The massive amount of paperwork, documentation, and record-keeping must not only be created, but must be constantly updated after every phone call, email, or visit with a healthcare professional. Whether the parent keeps paper records, or opts to utilize electronic applications such as the Personal Health Record or PHR, current and up to date information is critical in the case of special needs or medically complex children as they can suffer a medical emergency at any given time due to severe medical conditions. Accurate and updated medical information allows for quicker care.

Lastly, parents of special needs and medically complex children have admitted that Patient Health Record systems and Patient Online Portal systems have had made their children's medical care handling easy for them. These systems help in proceeding the smooth flow of medical care for the special needs child. Moreover, any informal

medical information such as insurance details or any emergency contact number can be readily available through these systems (Song et al., 2017). The mobile personal health record system (MPHRS) allows the parents to maintain and regulate the data of their child's disease, their lab results and other clinical measurements, all these pieces of information are converted into a digital document by HL7 CDA and uploaded on the application (Sunyaev et al., 2015). This information is then saved and regularly updated according to the progress in the patient's care and treatment of the child.

Ease of Access

The use of mobile applications, different patient centered online portals (Barry & Edgman-Levitan, 2012), electronic and patient health record systems (Ganju et al., 2017), telemedicine and telehealth (Bove et al., 2019) are all the different means through which patients, their families, and also physicians can get easy access to the health care information.

Although the literature labelling all of these health informatics technology as "easily accessible", the questionnaire results showed the contrary. The majority of the sample population (that included female parents or caregivers of medically complex children) reported access to these health care modalities as "**Difficult**". There are many difficulties and obstacles that patients and/or their family members face while accessing and managing the health-related information regarding their special needs or medically complex child. Although, remote medicine and the shift of the medical care to online versus face to face has changed healthcare for many populations and demographics of patients, the question remains whether accessing and understanding health technologies requires an educational background (Pathipati et al., 2016).

Knowledge of the Internet is critical. In an era of Smartphones, iPads, and the Internet everyone is familiar with how to access technology in some manner. But, lack of basic skills such as operational skills, formal skills, strategic and informational skills prove to be a hurdle while accessing online health care portals (Van Deursen, 2012). Furthermore, problems related to saving an online file or any sort of a picture on the computer, dealing with online operational tasks and completing an online form and bookmarking a website page were some of the problems that made online access for parents troublesome.

The results of the questionnaire showed about 5% of our sample population of parents to medically complex children found it “**extremely difficult**” to infiltrate and manage necessary medical information regarding their children’s condition and treatment. Either the privacy policies of the healthcare organizations do not allow them to get access to the EHR systems or they do not have basic medical education to manage and organize their child’s health related data. The availability of mobile applications, internet access, complex medical terminologies and financial issues are some of the hindrances that parents lacked in managing the health care data.

Family Centered Approach

Literature cannot emphasize enough on importance of family-centered care, especially while treating young children who are medically complex (Hill et al., 2017) (Zheng et al., 2020). Since in this type of health care delivery approach, the health care provider considers the whole family of the special needs child as a whole unit, the treatment plan is designed by keeping in mind the whole family—including the patient. The questionnaire asked parents about a preference of a family-centered approach over

any other, and the majority of parents and caregivers answered positively while only a few did not have a good opinion about it. Such a response would suggest that healthcare providers should evaluate the benefits of a family-centered approach that encompasses a holistic and family-inclusive route rather than a patient centric approach while treating a medically complex child. Moreover, it also depicts that more general public awareness is necessary in order to normalize the family centric approach.

The population sample who gave affirmative response to the survey question were then asked the reason behind preferring family-centric approach to medical care of their special needs or medically complex child. They had numerous reasons to back up their answer. The majority of the answers were related to the de-escalation of anxiety in all of the family members and improvement in planning of medical care for their children.

When parents are fully aware of the disease course and the probable and on-going treatments for their loved one, they feel less stressed out and more confident in regards to their child's health (Zheng et al., 2020). This not only helps—in general—with their own mental and physical health but also any other children and members of the immediate family. This empowers parents and caregivers because they feel more in control.

When parents and other family members have access to all the medical information of their medically complex children they feel relaxed, satisfied and more positive of their child's future (Hill et al., 2017). This is the reason why a family-centric approach to healthcare is more favored by parents—because it not only provides better outcomes for their special needs and medically complex children but also protects them from mental and other physiologic illnesses.

Additionally, when family members, such as siblings, see that they are involved during the process of treatments for their special needs or medically complex sibling, they feel more inclusive and closer to the patient. It sends positive energy towards them which leads them to work harder for the betterment of their ill family member by looking for ways to include the patient in daily routines and activities and generally helping them as much as they can because they become emotionally attached to the sibling (Zheng et al., 2020). According to a recent study, more than 84% of the parents discussed their special needs child's school medical report with their other family members and this encouraged family members to become involved in the care and decision making of the special needs child (Ide et al., 2020). This shows the importance of actively involving family members in the care and support of a special needs or medically complex child—an ideal approach to family-centered care.

Health Informatics Empowerment

The questionnaire included this last question about whether health care providers encourage parents and caregivers to utilize health care informatics in order to communicate and exchange medical information about their special needs or medically complex child. Surprisingly, the majority of the parents responded with a negative answer. Although there were parents who gave an affirmative response, the percentage of contradictory responses outweighed the affirmative. It is reported that health care providers did not take an active interest to educate and inform parents and caregivers of special needs and medically complex children about how to leverage health informatics and technologies to complete tasks such as accessing lab reports, imaging reports, and other personalized and confidential medical data of their children via a phone app or an

online patient portal. This is the main reason why the normalization of healthcare informatics has not been achieved yet because the primary source of educational awareness—healthcare providers—do not spare the time to educate and train and merely only focus on the exam within the 15- or 30-minute appointment slot.

As all of the respondents of the survey were females, the minimized access and use of healthcare apps, healthcare informatics, electronic patient portals and other forms of medical information technology could be explained by the busy schedules that the mothers of special needs and medically complex children have. Juggling between home, work, and immense amounts of coordination and oversight for special needs or medically complex children, the participants' responsibilities do not permit them enough time to learn new technologies, attend training or educational sessions, or—in some cases—call and wait for someone at the physician's office to explain how to use these technologies.

This survey also points out the lack of critical and ongoing conversation between the healthcare providers and the parents/caregivers. Healthcare providers have a strong responsibility towards sharing information and knowledge with their patients, and in the case of the pediatric population, with the parents and families of patients. They should advocate, promote, and teach the parents of special needs and medically complex children that access of use of health informatics applications to monitor and communicate about their child's health and treatment is beneficial not only for their child, but for themselves as well. Leveraging health informatics technology and applications improves health outcomes for their special needs and medically complex child but also promotes empowerment and control as the “gatekeeper” of his or her child's medical information (Ide et al., 2020).

Summary of Findings

This study showed that the top three concerns that parents and caregivers of special needs and medically complex children have with leveraging available technologies in the care of their children are: 1) a lack of interaction with the healthcare provider. 47% of the participants reported that they do not feel as if the healthcare provider is paying attention to them and feel ignored when physicians turn their backs to them in the exam rooms to document in the computer which makes it difficult to know if the healthcare provider is capturing and documenting accurate information. 2) Safety/security of sensitive personal and medical information and unfamiliarity with online portal technologies. 42% of the participants reported that their healthcare provider was not helpful in setting up proxy access for parents to gain access into their child's medical record. 3) Flow of information is not seamless. 47% of the participants reported that they have long waits for responses to emails and communication via online/electronic portal applications. System and processes are disjointed. All participants in this research project owned a Smartphone, computer, or tablet that they used to access some type of online, electronic application related to health.

Future studies about the frequency and use as well as satisfaction with different health informatics applications and portals can help with understanding if parents who devote their time to coordinating healthcare for their special needs and medically complex children prefer digital communication or face to face communication with healthcare teams. This study also showed that younger parents (those in their 20's) were more likely to leverage and trust technology when communicating and coordinating with

their child's healthcare team. This can most likely be attributed to greater knowledge and ease with technology for this age group.

Conclusions

This study shows that although there are many advancements in technology which have been helpful and important tools for parents such as telehealth/telemedicine and online informatics applications such as patient portals, that the majority of parents are not made to feel empowered to utilize said tools and applications. Most of the participants felt that their child's information was not easily accessible because of legal requirements such as gaining conservatorship or guardianship before being granted proxy access to online portals and applications. Participants, regardless of age and education felt that they were not deemed the subject matter experts on their child and their child's medical condition by healthcare professionals. This leads to self-doubt and can potentially negatively affect the parents desire to become empowered in the care and treatment of their child.

Recommendations

This research study will aid parents and caregivers of special needs and medically complex children as well as healthcare delivery team's insight into the barriers and challenges that parents face when trying to coordinate health information and care for their child through electronic, online applications. Identifying the barriers and challenges that parents must overcome before being able to take advantage of health informatics applications such as telehealth/telemedicine, online patient portals, and electronic health records will help promote a review of the current electronic communication systems and technical standards and requirements. Unless healthcare systems can commit to availing

and deploying technology that is explicitly designed to provide care for the most vulnerable patient population, health informatics technologies may further entrench health disparities for the population studied in this research project. A review of new health informatics technologies and applications in another 3-5 years will help to identify whether healthcare systems have committed to availing and deploying technologies that promote health equity.

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