Analysis Of Responses From Survey For Telehealth/Medically Complex Children

Posted on October 5, 2022

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

The society that we live in is brutal. It is tough for a person to live a normal life after he has been declared a little different from others. Hence, when it comes to sharing a different nature from any other human being, that person thinks of so many different scenarios of humiliation. Similarly, when a person suffers from an ailment, he is tagged as “differently able” from other members of society; therefore, even when it comes to sharing personal history with their doctors, they find it hard to swallow the pill. The same case applies to parents of medically complex children. There are concerns and speculations when it comes to sharing medical information face-to-face with the primary care doctor of their children. Thereupon, the first question in our questionnaire was to ask our sample population of parents about the concerns they have when they share their child’s medical history with their medical practitioner face to face.

One of the main concerns of parents regarding sharing confidential medical information of their medically complex children with their physician is a 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 among physicians and improvement in the respective room has been a constant concern since the dawn of the medical era. Empathizing with their patients at emotional and human levels is very much required in the medical profession. 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 with 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 parents of disabled and medically complex children, they 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. The majority of physicians rely on bookish knowledge and evidence-based practice but forget about the human nature of the profession. Healthcare workers who confide with the complementary therapies and spare enough time to listen to the patients in detail allow their patients tend to revive their sense of identicalness and selfhood (Robertson, 2017), as empathy and good communication skills have been linked to higher parent satisfaction and improved health outcomes (Berman & Chutka, 2016). Since the examination of a medically complex child requires more time than an adult patient, parents look up to physicians who examine their child thoroughly, communicate, and understand not only the parent’s situation but also the child’s condition.

Another main concern of parents regarding their physician’s appointment with their medically complex child is the feeling of embarrassment and anxiety 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 with their patients and pay proper attention to their parents leave them embarrassed and feeling anxious (Robertson, 2017). Studies have shown that about 50% of the physician’s time is spent on the 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 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 for their children in the end.

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

The second question of our selected questionnaire was about the concerns 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 concerns of the child’s medical information. The medical information stored and delivered via an electronic device always leaves speculation in the minds of the parents related to the secured perseverance of the confidential information of their child’s health. Electronic media uses various technologies in the medical field, one of 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 telecommunication devices in order to deliver medical information about their children to the doctor, are very much worried about the fact that the information would actually be

delivered to the respective physician or would go unnoticed or carried on to some other personnel. The messages that are being shared either in the form of texts or images can now be deleted by the sender's command on the recipient's phone. On the other hand, patient authentication and preserving obscurity are also some of the main concerns when using telemedicine. This can generate confusion regarding the respective patient's data (Ginige & Maeder, 2018) (Miller et al., 2020).

The world of medicine is expanding its branches into technological advancements with its own pros and cons. Health informatics has introduced different interfaces that have eased the daily work of healthcare professionals. Electronic health record systems Electronic Health Record (EHR), telemedicine and telehealth, computerized physician's order entry (CPOE), Clinical decision support system (CDS), Electronic patient portals, etc. However, all of these technical systems come with their negative aspects, which has made patients and their parents very concerned. Workflow problems, communication problems, technical problems and consumer-related problems are some of the issues that come with the operation of electronic healthcare systems (Vanderhook & Abraham, 2017). Healthcare workers are not trained to operate these newly introduced systems; hence, it is difficult to maintain the workflow and appropriateness of the medical data. Moreover, parents of medically complex children and adult patients also do not have any knowledge related to these systems; therefore, they are unaware of how to properly administer the required information into the system. This is the reason why parents are anxious and confused about the use of such advanced technologies because they are unsure whether the medical information of their children would be delivered directly to the respective physician or might get stored in any other part of the electronic health record.

Health informatics has opened portals to so many essential technologies; for example, the electronic health record system (EHR) has decreased the frequency of ambulatory locations where parents of critically ill children suffer from Chronic Obstructive Pulmonary Disease (COPD) etc. (Ganju et al., 2017). Paediatrics is one of the many branches of medicine that has taken full advantage of telemedicine in the form of teleconsultation, teleresearch and tele-education (Burke et al., 2015). However, public awareness and education regarding the evolved technology among parents are as important as the education of the health care provider regarding it so that the significant medical information of the ill children might not get missed by the doctors in the sea of enormous medical data and their chance of receiving optimal and accurate medical services.

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

When patients or parents of critically ill children decide to use any means of telecommunication for the transfer of medical data to their healthcare provider, obstacles like communication barriers come their way. 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 to name a few. There might be a delinquency in the network system on either one or both of the receiver's and the recipient's ends. All these communication barriers are the reasons why the telecom industry is moving slowly in the medical area. 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 our 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 from 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 may or may not receive data, etc., due to all such possible reasons a physician might not be able to attend to the calls, text messages or emails. It seldom happens that important e-mails might be transferred to the spam folder; therefore, the physician might never have the chance to go through the medical files.

All these barriers could still be resolved if a doctor or the health care provider hires an assistant who looks up and organises the incoming medical data accordingly. But this again would create another barrier or concern for the parents, which is privacy. According to our survey, privacy issues regarding the sharing of medical information of their children were the second most common concern for the parents (Marcin et al., 2004). 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 a 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. In addition to this, the fear of leaked confidential information adds up to the agitation they are already facing.

Healthcare informatics has eased healthcare institutions in their daily tasks, but at the same time, the newly introduced technologies are difficult to understand and utilise. Hospitals and different IT organisations arrange various workshops to train healthcare providers and doctors who are supposed to use these technologies. However, there are no workshops arranged for the parents of medically challenged children. Therefore, the issue was also recorded as one of the main concerns among them when using electronic means to seek medical care (Vanderhook & Abraham, 2017). Alluding to this discussion, doctors prefer using the time spent learning new technology over-treating their patients in real-time (Gawande, 2018). While doctors prefer not to waste their time sitting on computers, there is no organisation that works for the families of ill children so that they might also be able to learn these technologies. Education related to the continuously evolving technology in the medical field has caused disquietude among many people, not only patients and their families but also clinicians (Stanberry, 2000).

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

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 effective in pediatric cases as teleconsultation has made healthcare delivery very accessible to parents of young children and newborns (Burke et al., 2015). But every computerized technology comes with its cons. A lot of technological deterrence has been recorded, especially by parents who opt to use such technologies for their children's medical conditions. According to our survey, one of the main and top technological hindrances faced by the parents was the legal justifications and technological set-ups for young adult or minor children. As telemedicine and other forms of healthcare informatics ease access to healthcare facilities, parents rely on such technologies for their child's care while they carry on with their office tasks and daily routines. However, these technologies require legal confrontations and guardianship in order for young children to get access to them. Hence, parents find it difficult to co-op with the safekeeping of their children while at the same time working tirelessly to legally authenticate the use of healthcare informatics for their children.

Licensing and legal liability are holding the expansion of healthcare informatics (Mitchell, 1998) in most parts of the world and making the authorities ponder over the solution of the matter. This is the reason the Health Insurance Portability and Accountability Act (HIPPA) and the Affordable Care Act (ACA) are in constant pursuit of making the legal issues of healthcare informatics as easy as possible for the general public (Verduzco-Gutierrez et al., 2020). Asynchronous communication via telemedicine is now amenable to the privacy bylaws, allowing the parents of ill children to share their required medical information with their physician. Similarly, the Health Information Technology for Economic and Clinical Health Act (HITECH) and the current 21st Century Cures Act (Cures) have committed to providing easy-to-handle medical information to the general public in the most cost-effective way possible (Bove et al., 2019).

Electronic health records, patient health records, or online portal systems are created to simplify the input, processing and eventual output of patients' medical data. However, as new as these technologies are, the general public has no knowledge about them. However, it is the duty of the healthcare providers to educate and be aware of them and guide them throughout the technical procedure because the healthcare organisations arrange various workshops, conferences and training sessions for the healthcare providers to get them used to such technological advancement (Gawande, 2018). On the other hand, patients and their parents/guardians are not given manuals to help them cooperate with the new computer technologies. This was yet another main obstacle that was recorded in our survey related to the hindrances of sharing children's medical data with the health care provider.

A fragmented and disrupted flow of information between the clinicians and the parents of medically ill children is also a significant barrier when using any form of healthcare informatics. When a parent or a guardian uploads any medical data on the electronic portal or forum, that data is not only stored and processed in the clinician's EHR system but also in the hospital's EHR and national health data registries (Smaradottir & Fensli, 2019). This leads to either a delay in response from the healthcare team or results in a fragmented flow of informational responses between the patients. Parents have to wait in the "virtual waiting room" for several hours for their medically complex children just to get by different relaying systems in order to reach their general physician.

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

Patient-centred as well as family approach is essential to effectual healthcare delivery (Barry & Edgman-Levitan, 2012) (Shields, 2010). As much as it is emphasized in the literature, it is not at all being implicated practically. When the parents of critically ill children were asked about their involvement by the clinicians in the clinical decision-making of their child's health, the maximum responses that were recorded were negative. The majority of the parents were left out of the process when important decisions were made regarding their child's health. Under-aged and young children do not have the capacity and authority to make correct medical decisions for themselves. In such cases, their parents or guardians are held responsible for them, as they are the ones who take care of them and are fully aware of their medical situation. However, although this concept has started to gain pace, it is still not appreciated and practised in healthcare settings.

The family-centered approach to medicine has been in books for the past 40 years (Bamm & Rosenbaum, 2008). We cannot emphasize the importance of this concept in pediatric healthcare delivery more. Collaboration between parents and healthcare workers is necessary for better treatment delivery, as children cannot report their symptoms themselves. Moreover, it not only enhances the healthcare teamwork members but eventually improves the treatment outcomes in pediatric cases. Yet, the practicality of this core concept is still absent from the medicinal field. According to a study that was conducted a few years ago, half of the parents of critically ill children were satisfied with the concept of Family Centered Concept (FCC), while the rest of the parents were not (Hill et al., 2017). Parents not being provided with regular updates on their child's health and enough space to settle themselves at the bedside also felt left out of their child's treatment process, leading to a state of confusion and bewilderment related to the treatment course of their children.

According to the Institute for Patient- and Family-Centered Care (IPFCC), the four core concepts that are the basis of family-centred care (FCC) are: respect and dignity, information sharing, participation, and collaboration (Hill et al., 2017). Empathy and good communication skills are the basic demands of the doctoral profession that would compensate for the family-centred approach. Parents looking after

their children in a pediatric ICU reported inappropriate, coldhearted and adamant behaviour from the healthcare providers that lacked commiseration and humaneness. Act of kindness, such as the introduction of the physician to the family members and communicating directly with them, is often found to be absent in most doctor-family interactions. 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. However, doctors lack this basic gesture; hence, families do not feel dignified, involved and respected in their child's health care.

Comprehending parents in the medical rounds of the pediatric intensive care unit, which is one of the pillars of the family-centred care approach, increases their confidence and satisfaction with the doctors and the health care delivery they provide. However, a fraction of parents feel stressed and confused by the multiple options being discussed in the rounds and also by the formidable environment of the ward or the ICU (Hill et al., 2017). Collaboration between the parents and the doctors is also one of the key elements to promoting a family-centric approach in Healthcare delivery, and in the current time, this is the only thing that is lagging behind. This is why there is always a mixed review of the FCC among healthcare providers and parents, and it is one of the main barriers to normalizing it.

What strategies have you used to overcome barriers to effective communication with your child's healthcare provider/specialist? Top 3 strategies collected from the data responses:

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 portray a potent picture of themselves, leading to a great sense of confidence and trust from their patients. On the other hand, good communication with patients can ultimately lead to a detailed history and medical information, which would eventually lead to a better healthcare outcome for them. Unfortunately, doctors and patients both face a number of communication barriers while sitting in an examination room. These barriers affect both parties, which would be detrimental in both cases. The good thing about this scenario is that both doctors and patients or parents\guardians of young children opt for different strategies in order to negate such barriers and promote high-end healthcare services, giving positive and fruitful responses at both ends.

Our survey included a question for the parents acquiring different strategies that they use in order to overcome these communication barriers. The top strategy they use is the extensive collection of all the useful information related to the medical condition of their children before going for their medical appointment. For this purpose, they jot down the necessary stuff, including their children's detailed medical history, lab reports, imaging reports, and any side effects of medications or allergies so that if

doctors require them, they can provide them instantly. Individualised Education Program (IEP) is a legalised document in schools in the United States of America that contains all the necessary medical information of a special needs child. It is compiled with the help of the parents themselves and the child's primary care physician, who is closely related to the medical history of the child. Parents are supposed to get a detailed copy of this document every time it is updated so that they can provide it to other healthcare specialists later in time (Hill et al., 2017).

Children with chronic mental health conditions such as Autism, Attention Deficit Hyperactivity disorder (ADHD), Down syndrome, etc., can show unexpected behaviours at unexpected times. Often, parents have to cancel doctor's appointments just because their children do not cooperate with them. In order to overcome this difficulty, they have opted to use telemedicine and telehealth services (Burke et al., 2015). These technologies help them to communicate with their primary care physicians from the comfort of their homes. They use teleconsultation services for consulting their children's medical conditions without diving into the hefty situation of dragging their children all the way to the hospital. In this way, the medically complex children receive their medical care no matter what.

The last but most important solution to the communication barriers between the parents of medically complex children and their parents is a 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 a better future for their children (von Thiele Schwarz, 2016). This approach not only saves time for both the parents and the doctors but also creates a positive environment where everyone is focused on the same goal with positive energy and good vibes. This has an indirect effect on the mental condition of the parents as well. Parents of medically complex children can suffer from depression and anxiety with the passage of time (Cohn et al., 2020). At the same time, having confidence and a positive mindset can decrease the probability of such unfortunate events among the parents.

What are some ways that you ensure your medically complex child's medical record/information is accurate and up to date? Top 3 identified approaches by parents:

Throughout our survey, we recorded different problems and obstacles that parents face in order to get complete and optimal care for their medically complex children. Whether they opt for a teleconsultation to seek remote medical care or a more traditional face-to-face approach, despite these problems that they face, they have promulgated various ways to overcome those challenges. Our survey, in its later parts, intends to accumulate the major solutions that parents utilise to ensure a smooth flow of health care delivery for their ill children and also various ways through which parents organise their child's medical data so that they are up-to-date and get accurate medical information.

These steps make it easier for them, as well as the physicians other than their child's primary physicians, to get all the detailed medical and drug history that is otherwise lost when the primary care physician is changed because of the hospital's organisation and privacy policy do not let the patient or his family members get access to the electronic health record of the patient once he has left the hospital.

The first and foremost thing that parents do to remain acquainted regarding their children's medical information is to keep a detailed record of their history and present complaints and make future decisions that might have to be taken in response to some untimely events. Personal Health Record (PHR) is a method of saving and organising personal health information and having access to it anytime (Song et al., 2017); only in this case, the parents of the children do the task. A personal health record system helps patients readily access their complete medical history and treatment plans even when they switch physicians. Maintaining PHR for their children helps them with the hefty work required while making multiple phone calls, emails, faxes, a bunch of paragraphs, and documented work in order to obtain optimal medical care for their children.

During our survey, oftentimes, parents were of the view that it is quite arduous for them to remember the extensive and over-complex medication lists of their medically complex children, especially when they shift to a new practitioner. In addition, when at home, suddenly, the health condition of the children gets complicated; they do not know which medications they can take over the counter, and the anxiety and tension make it difficult to search for an emergency number at that time. However, the PHR system helps them manage all these situations in an orderly. As opposed to Electronic Health Record systems that only give access to physicians and patients only till the time they are under their care, these systems can give authorisation to physicians as well so that they can counter-check the medications and the allergic reactions to any medicines if implicated. Similarly, parents can note down any emergency protocol that might come in handy in case of any medical emergency, such as a fit attack or severe asthma exacerbation.

Lastly, parents of medically ill children have admitted that Patient Health Record systems and Patient Online Portal systems have made their children's medical care handling easy for them. These systems help in proceeding with the smooth flow of medical care for ill children as they give doctors who are involved in their medical care delivery the ability to redo any medication prescription or go through their medical history in detail. 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 disease and the treatment their child is going through.

How easy is it for you to access & manage your medically complex child's health information? Responses from the survey:

There is enormous literature present that has provided unlimited ways of managing and accessing medical health care information not only for the patients themselves but also for the parents, guardians or their family members. Initially, the use of paper had been very easy and accessible for many people. They would simply document everything related to the progress or decline in their treatment course. The list of their medications, allergies, emergency protocols, contact numbers, and all other important documentation were noted down on a few pieces of paper. However, as time has advanced and eventually has led to the advancement in so many other fields, health information management is one of them. The use of mobile applications, different patient-centred online portals (Barry & Edgman-Levitan, 2012), electronic and patient health record systems (Ganju et al., 2017) (Song et al., 2017), telemedicine and telehealth (Bove et al., 2019) are all the different means through which not only the patients and their families but also their physicians can get easy access to the health care information.

Albeit the literature labelling all of this health informatics technology "easily accessible", our survey showed the contrary results. The majority of our sample population, which included female parents or caregivers of medically complex children, demonstrated access to these healthcare modalities as "Difficult". There are many difficulties and obstacles that patients and their family members face while accessing and managing health-related information regarding their medically complex children. Although remote medicine and the shift of the medical data saving paradigm to online in cities and to some extent in the rural areas as well have made life undoubtedly credulous, the enigma that arises is whether it is necessary to have a basic educational background in order to access such advanced health care informatics? The answer, to some extent, is yes (Pathipati et al., 2016).

The first and foremost troublesome situation is that people, especially those living in remote areas or even in developed areas, do not have knowledge of the internet, and they do not know how to surf the web browser. Lack of basic skills such as operational skills, formal skills, and strategic and informational skills prove to be a hurdle while accessing online healthcare 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, completing an online form and bookmarking a website page were some of the problems that made online access for parents troublesome. A study that aimed to address problems related to online-based access to medical information showed that people get distracted by the various advertisements and banners that are posted on medical websites. Hence, they were unable to extract the required information on time.

Our survey 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 organise 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 leave parents behind in managing their healthcare data. Although healthcare informatics has led the approach of people living in remote areas to get access to the most advanced medical care via telemedicine and telehealth, people having low educational backgrounds would not have the ability to use the technology as they should. This has created a huge responsibility for healthcare providers to educate them as well as make them aware of such pliable healthcare technology.

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-centred" approach to healthcare for medically complex children is beneficial? Responses from the survey:

Literature cannot emphasize enough the importance of family-centred 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 ill child as a whole unit, the treatment plan is designed by keeping in mind the whole family, including the patient. During our survey, when parents were asked about their preference for a family-centred approach over any other, the majority of them answered positively, while only a few did not have a good opinion about it. Such a response should direct our medical practice more towards 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 that gave an affirmative response to our survey question was then asked the reason for preferring a family-centric approach to the medical care of their 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 the planning of medical care for their children. When parents are fully aware of the disease course and the probable and ongoing treatments, they feel less stressed out and more confident regarding their child's health (Zheng et al., 2020). This not only helps in general with the mental stability of themselves but also of their ill children as well. They feel more pumped, positive, and energized while taking care of their children.

When any member of the family is ill, the whole gets stressed out, leading to a general disturbance in the entire household. This situation is further escalated when a child of the family is ill and suffering from a chronic disease. Parents and other caregivers get stressed out feel anxious about the forthcoming and, which might eventually lead to depression and other mental frustrations with time. They have a higher chance of acquiring mental disorders such as depression, anxiety as well a positive chance of developing cardiovascular diseases that eventually could lead to mortality, especially in the case of mothers of such children (Cohn et al., 2020). 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 about their child's future (Hill et al., 2017). This is the reason why the family-centric approach is more favoured by parents because it not only provides better outcomes for their children but also protects them as well from mental and other physiologic illnesses.

Basically, when family members see that they are being involved in the process of generating a treatment plan for their medically complex child or sibling, they feel more inclusive and close to the patient. It sends positive energy towards them, which leads them to work harder for the betterment of their ill family member by surfing the internet for more treatment options, getting themselves updated every now and then regarding their treatment course and helping them in every manner to get better as soon as possible (Zheng et al., 2020). According to the latest study, more than 84% of the parents discussed their child's school medical report with their other family members, and the majority of them believed that up-to-date medical health reports helped them encourage themselves to seek better healthcare for themselves as well as for their children as well (Ide et al., 2020). This shows the importance of including family members in healthcare-related discussions, which can improve not only the health of the ill child but also of the family members.

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 to use evolving information technologies for information exchange?

Healthcare informatics has been engraved with importance in our lives since the digitalization of the medical field. It has not only decreased the financial cost of medical facilities, eased its access to people living in remote and underprivileged areas, increased the speed of health care delivery, but also upgraded the health care provider's database system. People who are aware of this remarkable form of healthcare delivery take full advantage of it. But people who do not know about these

technologies, for example, mobile health applications, online patient portal systems, electronic health record systems, etc., need to be educated as well. So that everyone could easily be a part of this digitalized era and could use the full potential of what it has to offer.

Our survey included the last question about whether the health care providers encourage the parents to utilize health care informatics in order to exchange their children's medical data with them. Surprisingly, the majority of the parents gave a negative answer. Although there were parents who gave an affirmative response, the percentage of contradictory responses outweighed the affirmative. No healthcare provider ever informed them about the ways of 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 yet been achieved. The primary source of educational awareness, that is, healthcare providers, does not spread the word, and they only focus on the treatment and its consequences.

As all of the respondents of our survey were females, that is, mothers of medically complex children, the lesser use of healthcare apps, healthcare informatics, electronic patient portals and other forms of medical information technology could be explained by the busy schedules they have in their homes. Juggling between home and work responsibilities does not give them enough time to surf the internet and update themselves on their child's medical situation. Here comes the reliableness of healthcare providers to motivate and push parents towards using healthcare informatics. But these times have led to a decrease in patient-doctor communication levels where the doctor only focuses on the treatment of the disease physiologically but does not consider the mental and physical impact it could have on the patient as well as their families (von Thiele Schwarz, 2016).

This survey also points out the lack of conversation between doctors and patients. Many studies have reported that patients or their parents, in the case of paediatrics, feel hesitant or embarrassed in front of their practitioners and their primary care doctors. Instead of making them feel comfortable through easy talk, way contact and handy gestures, just focus on their disease and its treatment (Liu, 2020). If there is a build-up of healthy doctor-patient communication, then helpful information could be shared. This could include a consolation, a positive yet realistic picture of their child's future and an encouragement to use healthcare informatics for their own betterment and ease.

Doctors are the sole bearers of knowledge and all the latest information related to medicinal advancement and the information technology related to it. They have a strong responsibility to share this knowledge with their patients and, in the case of the pediatric population, share it with the parents and families. They should find it their obligation to make their patients and their family members aware of all the different ways and options they can find to reach optimal healthcare delivery. They should teach the parents of medically complex children that using healthcare informatics to update themselves on their child's health and getting access to it would improve not only their child's health but also their mental and physiologic health as well (Ide et al., 2020).

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