

# My Child Has What? The Most Effective Means of Communication When Delivering a Difficult Diagnosis to the Parents of a Pediatric Patient

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MY CHILD HAS WHAT? THE MOST EFFECTIVE MEANS OF  
COMMUNICATION WHEN DELIVERING A DIFFICULT DIAGNOSIS TO  
THE PARENTS OF A PEDIATRIC PATIENT

by

NIDHI SETHI

A thesis submitted in partial fulfillment of the requirements  
for the Honors in the Major Program in Nursing  
in the College of Nursing  
and in the Burnett Honors College  
at the University of Central Florida  
Orlando, Florida

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Thesis Chair: Dr. Linda Gibson-Young

## **Abstract**

For the healthcare provider, disclosing a pediatric patient's difficult diagnosis in the form of an acute or chronic condition to the parents is a challenging task. Healthcare providers often feel unprepared when relaying the news of such diagnosis, and the parents feel equally unprepared upon receiving it (Pririe, 2012). This systematic literature review examined the various communication techniques used in the past, and the techniques' effectiveness in increasing parental satisfaction when first learning of the child's diagnosis. A scarce number of studies related to the most effective techniques were found in the literature, and even fewer were found that evaluated the techniques presented.

Overall, three of the most commonly occurring communication themes identified from the studies were: 1) Parents desired privacy during the disclosure and wanted a support system present (mostly a spouse); 2) The diagnosis must be given as soon as the healthcare provider suspected it, and; 3) The healthcare provider must emphasize the positive characteristics of the pediatric patient, as well as the patient's future with the diagnosis.

Both parents and providers agreed that further research is needed to identify effective communication techniques used during disclosure. The aim of the research should be to identify the most effective means of communication to increase parental satisfaction. Furthermore, all healthcare providers need collaborative and interdisciplinary training in delivering a difficult diagnosis to increase parental satisfaction.

## **Dedications**

I would like to dedicate this work to a few very special people.

First to my grandparents, Brij Kishore and Prem Kumari Taneja, who all the way from India continue to support me in ways only grandparents know how.

To my support system at home, my parents Ashwani and Sunita Sethi, who do everything and more to make me realize my dreams.

To my brother, Akaash Sethi, for whom one page of dedications, or even a poster, will not do enough justice.

To my family everywhere else, from one part of the world to the other, your love and support do more than I can say.

To my friends at the College of Nursing, thank you for helping me get through the rough spots, and being there to enjoy the good ones.

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## **Introduction**

The birth of a child is a joyous and memorable occasion. However, in the case of a child born with an acute or chronic disorder, the experience can be difficult and stressful for the parents involved. This literature review examined the most effective means of communication when relaying a pediatric patient's difficult diagnosis of a chronic disorder to the parents for the first time.

### *Background and Significance*

Up to 10% of children are expected to have a moderate or severe long-term health problem (Harrison & Walling, 2010). Communicating the news of a health problem to the parents is a challenging task for the healthcare provider. The news can be presented in various ways, including face-to-face, over the phone, or interdisciplinary with many members of the healthcare team present. The healthcare provider is faced with a challenging task when relating the news of a difficult diagnosis because parents often remember years later whether the experience was a positive or negative one (Wright, 2008).

The time of disclosure is a stressful one for parents, and the delivery of the difficult diagnosis is often dreaded by healthcare providers. A difficult diagnosis can be defined as an acute or chronic disorder that affects the future of the child. The disclosure has been described by parents as realizing the "loss of a perfect child" and is a life-altering experience (Body, 2001). In the literature, the delivery of a difficult diagnosis can be termed truth disclosure. The method by which the news is disclosed affects the parents' ability to cope and can have future implications in regards to the parents' relationship with the child.

Parents of children born with genetic anomalies often relate to this initial discussion of bad news. Although Down Syndrome is the most commonly occurring chromosomal abnormality, there are other disorders, both acute and chronic, deserving further research. Because of this, there is a clear need for more research on this topic and the reason for this literature review. To this day, few studies have examined the effectiveness of previously employed communication techniques when relaying a difficult diagnosis and most remain qualitative in nature with limited quantitative research conducted. Since little is known, this review will focus on the most effective means of communicating a difficult diagnosis to the parents of a pediatric patient for the first time.

## **Research Question**

What are the most effective means of communication when relaying a difficult diagnosis to the parents of a pediatric patient for the first time?

## Method

The first aim of the literature review focused on communication techniques nurses have used in the past when informing a pediatric patient's neurological disorder to the parents for the first time. Search terms included truncated keywords, "nurs\*", "parent\*", as well as "child", "brain disorder", "neurologic disorder", "communication", "bad news", "sad news", "parental satisfaction", "truth disclosure", and "disclosure." Because the initial search yielded few studies, the research question was broadened to include all healthcare professionals and all pediatric disorders (both acute and chronic). This systematic review of the literature was conducted to examine the most effective communication techniques used in the past when disclosing a pediatric patient's difficult diagnosis to the parents. Databases used to extract relevant studies included CINAHL Plus with Full Text database, MEDLINE, and PsycINFO.

A subsequent search that included the terms "acute and chronic disorders," along with "professional-family relations" yielded 1,217 results. The search results were narrowed by using the following relevant terms: "truth disclosure"; "sad news"; "bad news"; "pediatric\* disease"; "pediatric condition"; "pediatric illness"; "therapeutic communication"; "verbal communicat\*"; "nonverbal communicat\*"; "communicat\*"; "child\*"; "pediatri\*"; "family; nurs\*"; "role"; "healthcare"; "effective communicat\*"; "doctor;" and "provider". From the 657 results found, the search was further narrowed to include only "truth disclosure or sad news or bad news or communicat\*" and "child or pediatric or family and nurs\*" to yield 380 studies.

From these 380 studies, inclusion and exclusion criteria were employed. Inclusion criteria included: 1) using a pediatric population (0-18 years); 2) all healthcare providers (physicians, physician assistants, nurse practitioners, and nurses); 3) any acute or chronic condition, and; 4)

studies written in English. Exclusion criteria included: 1) any studies written before 1990; 2) communication of a difficult diagnosis between the parent and child and; 3) any studies written in a language besides English. Twenty-three studies were identified, and of those, one was rejected because it referred to the communication between the healthcare provider and the child, and did not focus on communication between the healthcare provider and the parents. Seven were rejected because the focus was on communicating end-of-life care to the parents, which is not relevant to this research question. Additionally, four studies were rejected due to non-peer review. In addition to the databases mentioned above, the reference list from each study obtained was reviewed for studies that pertained to the research.

After employing the inclusion and exclusion criteria to narrow down the results, 11 research studies were selected for this systematic literature review. Next, the level of evidence of each of the 11 studies was determined to find one level II study (randomized control trial), five level V studies (synthesis of descriptive or qualitative studies), four level VI studies (descriptive or qualitative studies), and one level VII study (expert opinion). Ten of the 11 studies were either qualitative studies, or evaluations of qualitative studies, and one was a quantitative study.

## **Findings**

In the 11 studies, two of which were quantitative and nine qualitative, parents suggested a total of 19 communication techniques to the healthcare provider to improve the disclosure process. Of those 19 communication techniques, the three most common effective recommendations were selected as the themes for further analysis as these themes were recommended in the majority of the studies. These themes included privacy with support present, timing of the interview, and stressing the positive characteristics of the child.

### **Privacy with Support Present**

Krahn, Lalum, and Kime (1993) interviewed the parents of 24 children with a developmental disability to determine the parents' satisfaction with the disclosure process. The authors' research questions asked what aspects of the disclosure process the parents liked and disliked, when the parents preferred to receive the disclosure, advice to the healthcare providers for future disclosures, and how the disclosure process could be modified to increase parental satisfaction. A majority of the parents interviewed suggested that the disclosure be relayed privately, such as in a family meeting room, with the fewest number of healthcare professionals present (i.e. only those directly involved in the child's care). Another concern focused on making sure the disclosure remain uninterrupted. Parents recommended the disclosure to occur face to face. Boyd (2001) explained that privacy and few distractions during the disclosure process allowed the parents to feel more accepted by the healthcare provider, and created a comfortable atmosphere where parents could ask questions freely. Some parents wished that only the diagnosing physician be present, stating that "white-coated team members" in such an emotional situation would only add to the stress that was already felt (Wright, 2008). Krahn, Hallum, and

Kime (1993) found that parents wanted the informing physician to personally know the child, and not necessarily be an expert in the field. Aside from the physician, other acceptable healthcare members include a perinatal nurse educator familiar with the family who could help the physician with more specific questions (Wright, 2008).

The concept of privacy also extended to after the interview, when parents reported that if needed, a private room should be made available for them to discuss and reflect on the meeting (Boyd, 2001; Wright, 2008). This theme would further increase parental satisfaction with the overall disclosure process.

Parents also stressed that some form of a support system should be present. In the study by Krahn, Hallum, and Kime (1993), 46% of the families interviewed suggested that this would be one of the biggest improvements when receiving bad news. The support made parents feel less alone, as well as reduced the burden of informing the other parent. Other reasons for support (especially spousal) was the reduction in information distortion (if one parent was not present during the interview), as well as being able to start the grieving process together (Boyd, 2001). In the case of a married parent, a spouse was preferred, and in the case of a single parent (usually a mother), a family member or close friend was preferred. Interestingly, one study found that even if the father was not available to attend the interview, mothers should be given the diagnosis first, and the physician should review the information once again when the father became available (Skotko, 2004). This study surveyed mothers of children diagnosed with Down Syndrome, and inquired about how the mothers felt at the time of diagnosis. A total of 930 mothers responded, and a majority stated that under no circumstances should the father be informed before the mother unless the mother was unconscious and unable to understand the

information (Skotko, 2004). Overall, the presence of a support system significantly reduced the feelings of parental stress during the disclosure process.

For example, after surveying 123 mothers of children with Down Syndrome, Murdoch (1983) found that 36% of the mothers reported dissatisfaction with the disclosure process. Along with parental dissatisfaction, many healthcare providers also reported feeling unprepared in the event of disclosing a difficult diagnosis to anxious parents (Charlton, 2000). Thus, more research, especially quantitative, must be conducted to increase parental satisfaction with the disclosure process.

Pueschel and Murphy (1976) surveyed 414 mothers of children with Down Syndrome to determine the mother's satisfaction when learning the child's Down Syndrome diagnosis. Analysis of the eight-question survey revealed that around 40% of the mothers felt the information provided regarding Down Syndrome was inadequate, and the physician was unsympathetic when delivering the diagnosis. In 1993, Sloper and Turner interviewed 103 parents of children with severe physical disabilities. Of these, only 37% of the parents were satisfied with the way the news was disclosed by the medical professional. Despite having two decades between the studies, both concluded that parental dissatisfaction at the time of receiving the diagnosis was high. Most of the research focusing on effective communication techniques to employ during the disclosure process was conducted before the 1990s, and the majority of the research centered on Down Syndrome.

### **Timing of the Interview**

The disclosure of a diagnosis can be relayed either before or after the birth of the child. Most of the studies found that parents preferred that the diagnosis be delivered as soon as the

healthcare provider suspected it. If the diagnosis could be made and confirmed prenatally, then that is when it should be disclosed. In the cases where the diagnosis was suspected postnatal, timing was also important. The suspected diagnosis should be given as soon as it was discovered, but only after the mother had time to recover from the birthing process (Skotko, 2005). Sheets, Baty, Vázquez, and Hobson (2011) interviewed 14 mothers whose children were diagnosed with Down Syndrome at the time of birth. The survey questions were open-ended and focused on what the mothers felt upon first learning the child's diagnosis, and later what the mothers thought would be the best case scenario a parent could have wanted during a disclosure. Mothers who had been informed of the diagnosis after the baby was born wished the news had been communicated sooner, i.e. as soon as it was suspected. Another reason for wanting the information as early as possible was that the mothers often felt "betrayed" and "in the dark" about the child's health (Krahn, Hallum, and Kime, 1993). Mothers felt afraid when the child was taken away for testing without informing the mother first. This was made worse because parents often felt the healthcare team was avoiding them and avoiding eye contact. This added to the already escalating stress on parent who now felt that bad news was imminent (Skotko, 2005; Wright, 2008).

Another suggestion is the inclusion of a short-term therapeutic conversation after the disclosure. Svavarsdottir et al. (2012) conducted an experimental study in which 76 families were divided into two groups: the control group whose children were admitted in the hospital for an acute or chronic condition, and who did not receive a therapeutic communication intervention; and the experimental group, who received a therapeutic communication intervention afterwards to determine whether the short-term communication increased perceived family support. The

conversation, initiated by the nurse, started by asking the family what current challenges were being faced because of the child's hospitalization; the impact of the hospitalization; what had been most and least helpful in similar situations; how the family could be helped best; and what the families wished for at that time. Although this study did not focus on first time disclosure of a difficult diagnosis, its findings can be extended and applied to the topic at hand. The study found that caregivers in the experimental group reported significantly higher perceived cognitive support after the conversation ( $p = .037$ ), though the family did not significantly report higher emotional support. This information can be useful when relating a difficult diagnosis as it significantly increased perceived cognitive support.

### **Positive Characteristics of the Child**

Fifty percent of the parents in the study by Krahn, Hallum, and Kime (1993) wanted the informing physician to relay the diagnosis positively and mention the positive characteristics of the child. Before the 1990s, few mothers reported that positive aspects of the child and the diagnosis were offered. Along with being positive, parents wanted physicians to keep negative opinions to themselves and instead focused on remaining positive (Wright, 2008). In one case, a physician told a mother that her child with Down Syndrome would never hold a job or live without assistance. Instead, it is recommended that the discloser help the parents feel well informed of the diagnosis and comforted. An example of a positive comment was a physician informing the mother of a child newly diagnosed with Down Syndrome that children with Down Syndrome are usually good and very loving (Skotko, 2008). One mother suggested that the informing healthcare professional use words like "normal," and put less emphasis on the negative outcomes of the disorder (in this case, Down Syndrome), such as stating the child and

parents would have a difficult time in the future (Sheets, Baty, Vázquez, Carey, and Hobson, 2011).

In conjunction with the theme of stressing the child's positive characteristics, parents wished for the child to be present during the interview. This way, parents could witness the interaction between the physician and the child. This accomplished the following: it showed that the physician was positive and comfortable in handling the child (making the parents more comfortable); and made it easier for the physician to point out characteristics of the child and dispel any misconceptions. Referring to the child as "disabled" was considered less desirable to the parents than using the phrase "infant with a disability." However, the best way to refer to the infant was by using his/her name. In the case of an unborn child, parents preferred using either "infant" or "baby" (Wright, 2008).

Aside from stating the positive aspects of the child and the child's future living with the diagnosis, parents also recommended the physician communicate current and up-to-date information. Skotko and Bedia (2005) surveyed 467 mothers with children newly diagnosed with Down Syndrome. The study found that the mothers reported feeling more emotionally positive when receiving up-to-date information than when the information presented was not current. This emotionally positive experience at the time of disclosure eventually led to a better parent-child relationship and better emotional and psychosocial development of the child (Skotko and Bedia, 2005).

## **Discussion**

Relating the news of a pediatric patient's difficult diagnosis to the parents for the first time should be a learned skill that improves over time, and is individualized to each situation. Horwitz and Ellis (2007) sent surveys to 206 doctors in Ireland who specialized in pediatric consulting, including disclosing a difficult diagnosis. Of the 113 doctors who responded, most reported feeling competent in delivering a patient's diagnosis of Down Syndrome to the parents. However, out of the 113 doctors, only 55 had personally delivered a diagnosis, with only 21% receiving feedback from the parents in regards to the experience of receiving a difficult diagnosis related to their child.

Medical students and nursing students do not receive enough education when learning to deliver a difficult diagnosis. Although techniques exist to aid students with the process, few guidelines have been established in delivering a difficult diagnosis. One model for teaching this important skill to their students can be found in the University of South Florida's College of Medicine where students in their oncology rotation are required to participate in a two-to-three hour session focused on communicating bad news to patients (Kiluk, Dessureault, and Quinn, 2012). The students are expected to deliver a difficult diagnosis to a patient, and the session is videotaped to evaluate later. Afterwards, the recording is reviewed by the students and instructor to highlight the positive and negative communication techniques employed by the students. A majority of the students (98.3%) agreed this exercise was helpful (Kiluk, Dessureault, and Quinn, 2012).

Disclosing a difficult diagnosis to a parent is generally a collaborative effort between physicians, nurses, and other healthcare professionals. As such, Wakefield, Cooke, and Boggis

(2003) evaluated a study in which 34 students (22 nurses and 12 medical students) participated in two sessions spanning two-and-a-half days that focused on how to deliver a difficult diagnosis. Groups were formed consisting of at least one medical student and one nursing student. Before each disclosure session, the group discussed the disclosure's content, and how best to disclose. The first session involved a 45-minute demonstration by a facilitator showing what was expected of the students, followed by students practicing disclosing bad news for two to two-and-a-half hours. During the second session, the facilitators demonstrated another patient scenario, and the students were given simulated patients to practice on. After the first and second sessions, the students were debriefed regarding performance. Though both medical and nursing students found the role-play beneficial, the nursing students reported having had less practice in this area as compared to the medical students. Thus, while simulations are beneficial, learning to communicate difficult news should be incorporated into the curriculum of medical and nursing programs alike.

Farrell and Langrick (2001) evaluated a workshop aimed at teaching healthcare providers to deliver bad news. In the workshop, 45 healthcare members (mostly nurses) were given scenarios to act out involving the deliverance of bad news in a pediatric setting. The scenarios involved the members (i.e., both nurses and doctors) working collaboratively to deliver the news, and later receiving feedback from the "patients". Seventy seven percent of the participants had not received any training in this field, but all agreed that training in this field was important. After completing the training, the participants were asked how effective it was. Both doctors and nurses found the training very helpful, with the majority stating that it should become a

mandatory element when being trained in respective fields. Thus, besides learning this skill during formal education, the teaching should be repeated to ensure understanding.

Although nurses may not communicate the diagnosis itself, nurses can be of great support to both the disclosing physician and the families. Nurses have often spent the most time with a patient and family during the hospital stay and can assist with individualizing the interview to that family's needs. Ahmann (1998) evaluated a study by Garwick et al. (1995) who found that nurses can conduct an informal evaluation to deduce the family's needs during the hospital stay. Aside from making the necessary arrangements for the disclosure interview (written materials, keeping the area a private one, etc.), nurses can be present as emotional support before, during, and after the interview. Because of the difficult nature of this news, parents can feel overwhelmed and shocked upon first learning the diagnosis. Nurses can educate the family after having learned the diagnosis, record and repeat information missed by the family, and use therapeutic communication techniques to increase parental satisfaction with the disclosure process.

### **Family, Cultural, and Language Considerations**

Few studies selected for this literature review mentioned the importance of individualizing the interview. This can mean having the information given in a parent's native language, having a woman communicate the information if that is more comfortable to parents, or allowing the presence of family members and friends if this increases parental satisfaction. For example, careful consideration should be paid to cultural differences. Sheets, Baty, Vázquez, Carey, and Hobson (2012) interviewed 14 Latina mothers whose children were diagnosed with Down Syndrome. Some mothers believed a personal mistake during the pregnancy caused the

child to have Down Syndrome while others attributed the diagnosis to an environmental, genetic or religious cause (i.e. the Down Syndrome diagnosis was a punishment by God). Consequently, the same mothers agreed that the disclosing healthcare provider should explain the organic cause and basic pathophysiology of Down Syndrome. Similarly, mothers also requested that the diagnosis be delivered in the language most clearly understood. In this study an interpreter delivered the diagnosis to mothers since the provider did not speak the mother's language, and thus cultural differences were not addressed. The mothers reported feeling less inclined to speak with the interpreter, and preferred a known support system, such as a family member or friend, to do the interpreting. However, having a person who is not trained in medical terminology is problematic. Flores et al. (2003) found that those not educated in medical jargon made more errors including false fluency, omission, substitution, and addition of information.

### **Recommendations**

Education in delivering a difficult diagnosis increases the disclosing healthcare provider's perceived competence, but not actual competence in the task. This means that though the healthcare provider feels more comfortable in delivering a difficult diagnosis, the diagnosis delivered may not be well communicated. Instead of educating the healthcare provider once during formal education, this particular training should be continuous and evolving based on new research. A suggestion is to create a certification that especially trains healthcare providers in delivering a difficult diagnosis. The education should also be collaborative, involving all members of the healthcare team (pediatricians, specialists, nurses), since the delivery involves several team members.

From a nursing perspective, nurses can conduct research on this topic and educate other healthcare providers on the communication techniques found to be preferred by parents during the disclosure process. Today, the majority of research has been qualitative in nature, with few quantitative studies conducted due to the subjective nature of this topic (perceived parental satisfaction). A recommendation would be for researchers to conduct mixed method studies that incorporate both the qualitative (parental satisfaction) and quantitative (parental satisfaction based on a scale) concepts. In summary, disclosing a difficult diagnosis is a skill that should be learned collaboratively, and improved over time with the objective of increasing parental satisfaction with the disclosure process.

A recommended prototype for an interview was developed and should be changed to fit each patient and situation

### **Interview Prototype**

Parents prefer knowing a child's diagnosis as soon as it is suspected. Thus, an interview should be set up as soon as the healthcare team suspects a diagnosis.

#### *Before the Interview:*

The collaborative team (obstetrician, pediatrician, specialist, nurses, social worker) should have a meeting to discuss:

1. What information should be presented at this first meeting, and to decide who should deliver the diagnosis.

Parents prefer a pediatrician who would be familiar to the family rather than an unknown physician. The disclosure's content should be subject to change based on the family's

reaction to the information. The information should also be culturally sensitive. This could mean having a translator present if the family prefers, having a woman deliver the diagnosis if more comfortable, or other culture specifics. The nurse should ensure that all materials are available, such as the patient's X-rays, test reports, etc.

2. How the information should be presented.

Written information is a must. The nurse should have pamphlets for each member present and, if permissible by the parents, should take notes during the interview to ensure nothing is missed.

3. Where the information should be presented.

A private area with no distractions (such as a family room) is recommended. A "Do not Disturb" sign may be used.

4. Who should be present.

The nurse should arrange for both parents to be present. If this is not possible, arrange for one parent (usually the mother) and either a family member or close friend to accompany the parent.

*During the Interview*

The healthcare team should be sitting near, and at eye level with the family.

1. Inform parents that the information may be difficult to process, and this is understandable by the healthcare team. The physician and nurse should encourage that the parents ask questions or comment whenever needed.
2. Information about the diagnosis should be up-to-date, factual, given at a slow pace, and in simple terms. For example, do not explain Down Syndrome as Trisomy 21, but instead

as a genetic disorder in which a person has 47 chromosomes (the genetic carrying component in a cell) instead of 46, an extra one being on chromosome 21.

3. Pay careful attention to the family's reaction, nonverbal cues, and verbal communication. The nurse can be of much assistance, often having spent the most time with the family during the hospital stay. If the family is not processing the information (eyes downcast, not answering questions presented), therapeutic communication techniques such as silence and touch should be employed. Allow for breaks during the disclosure process to offer time for the parents to ask questions or comment, and reflect upon the information. The physician should be gentle, caring, and most of all, empathetic during the disclosure.
4. If permissible by the parents, the physician should hold the child while explaining the positive characteristics of the diagnosis as parents feel the physician is accepting the child. In Down Syndrome, for example, mentioning that children do go on to work as adults, and have a good quality of life. Refer to the child by name (if s/he has one), or "child" if s/he does not have a name yet; in the case of a prenatal diagnosis, use "baby" when referring to the child.
5. The physician should state the proposed plan for the child's future, and include the family's involvement in the plan. Including numbers and information for support groups of the particular diagnosis is highly recommended by parents.
6. Allow time for questions and encourage the family to express thoughts and feelings as desired.
7. Ask the family if privacy after the disclosure is needed, and have a room available for families to reflect upon the news.

### *After the Interview*

1. Make sure the family has written information about the diagnosis, any important information discussed during the interview, and phone numbers of the healthcare team and of support groups.
2. Arrange for a follow-up meeting or a telephone interview with the disclosing physician within a month of disclosure to assess the child's health as well as answer questions and attend to the family.

(Boyd, 2001; Glascoe, F. P., n.d.; Krahn, Hallum, and Kime, 1993; Price, McNeilly, and Surgenor, 2006; Pirie, 2012; Sheets, Baty, Vázquez, Carey, and Hobson, 2012; Skotko, 2005).

### **Follow Up**

Parental stress after receiving the news of a child's difficult diagnosis does not cease after the disclosure. Parents can feel the stress of losing "the perfect child" even years after the disclosure. A collaborative effort with a social worker can help in making parents feel more at ease. Leon, Wallenberg, and Holliker (2013) studied the impact a child with a congenital heart disease (CHD) had on parents. The authors studied the stress parents feel after the disclosure process with the use of theories: the stress and coping theory, family systems theory, and chronic sorrow that face the pediatric patient with CHD and caregivers. In the case of stress and coping theory, Lazarus and Folkman (1984) believe caregivers go through stages of appraisal. The first stage entails the caregivers assessing the situation and the second stage involves identifying coping strategies. The family theory says that all interactions between family members and support systems impact the family's functioning. As time goes on, certain family members may feel more strain than others and this can lead to a decreased level of functioning and increased

stress between family members. Hence, special attention must be paid to the caregiver's family system to assess role changes throughout the child's illness. Finally, chronic sorrow is the process of grief a caregiver can go through. In the first phase, the caregivers go through periods of denial and grief, and some never leave this phase. In the second, the caregivers are able to work through this grief and move towards closure. Once again, as healthcare providers, it is of great importance to ensure the maximum amount of caregiver satisfaction keeping these theories in mind.

## **Limitations**

Not many experimental studies were found on effective communication techniques when delivering a pediatric patient's difficult diagnosis to the parents. The majority of the studies were either qualitative in nature, or literature reviews. Furthermore, the majority of the studies were surveys, sent out sometimes years after the diagnosis was disclosed, thus creating a high chance of recall bias by parents. Of those studies that proposed techniques to improve communication during disclosure, only one was evaluated. Another limitation was that several of the studies were written over ten years ago, thus the findings may not be generalizable today. Further, the studies focused mostly on Down Syndrome, and did not refer to other acute or chronic conditions. Also, there were no assessments used to help parents understand the medical diagnosis. Similarly, none of the studies objectively assessed the family's response to the diagnosis. Finally, the studies focused on a higher-level provider's (physician, nurse practitioner, physician's assistant) communication techniques when disclosing a difficult diagnosis, and thus "nurses" can be removed from this search as delivering a diagnosis is not within a nurse's scope of practice.

## Summary

Disclosing a pediatric patient's difficult diagnosis to parents is a task that healthcare providers find difficult and stressful. For parents, receiving a child's difficult diagnosis can mean the loss of a perfect child and affect the child's growth, and the family's relationship with the child. Few studies have been conducted to research effective communication techniques during the disclosure process in order to increase parental satisfaction. The studies that have focused on this topic have shown that disclosing a difficult diagnosis is a skill that should be learned and improved over time to increase parental satisfaction as well as the healthcare provider's competence in disclosing the diagnosis. Training in this field should be, if not mandatory, highly recommended, with certifications made available. Training workshops involving the collaborative efforts of many healthcare specialties (doctors, specialists, nurses) have been effective in improving the healthcare team's competence in the task, as well as improving the parents' experience. A total of 19 themes were identified from the studies selected, and of those, the themes were: 1) The news should be given privately with the parent having a support system present; 2) The news should be given as soon as it was suspected; and 3) The healthcare provider delivering the diagnosis should emphasize the positive characteristics of the child as well as the child's future with the diagnosis. With more research conducted and implemented in practice, it would be beneficial to create guidelines and ensure a more positive experience for all involved. Conducting more mixed methods research to create communication guidelines for providers to use during disclosure would help disclosing healthcare providers feel more competent, and increase parental satisfaction with the disclosure experience.

## **Appendix A: Table of Evidence**

Appendix A: Table of Evidence

Name, Year, Source	Method/Sample Size	Type of Condition	Purpose	Results	Limitations
<p>1. Boyd, J.R. (2001). A process for delivering bad news: Supporting families when a child is diagnosed. <i>Journal of Neuroscience Nursing</i>, 33(1): 14-20.</p>	<p>An analysis of previous studies to determine what caregivers want when bad news is delivered.</p>	<p>Neurodegenerative Disorders</p>	<p>To find the nurse's role during and after diagnosis of a pediatric patient with a neurological disorder, and to find what the caregivers want.</p>	<p>Caregivers want: empathy, sensitivity, and caring; allow caregivers to show feelings; provide time to talk and ask questions; provide privacy; arrange for both caregivers to be present; limit the number of professionals to be present; provide information (straightforward, honest, detailed); refer to other caregivers, support groups, and community resources; individualize the approach (most important).</p>	<p>-Literature review with no quantitative data.                      -Literature review involves cancer patients (and the protocols presented in the review have not been evaluated), not delivering bad news to caregivers or children.                      -Interventions in this study have not been evaluated.                      -Study was written over ten years ago.</p>

<p>2. Price, J., McNeilly, P., &amp; Surgenor, M. (2006) Breaking bad news to caregivers: The children's nurse's role. <i>International Journal of Palliative Nursing</i>, 12 (3): 115-20.</p>	<p>Literature examination</p>	<p>Palliative Care</p>	<p>To find the nurse's role when delivering bad news. Also, forms of communication that are useful when delivering bad news.</p>	<p>This study says that the nurse's role in delivering bad news is not well understood. Because the nurse is probably the one who developed a therapeutic relationship with the family and patient, that s/he should be the one to deliver the bad news.</p>	<p>-Literature review, not quantitative data. -Although a framework for delivering bad news has been offered, it has not yet been evaluated.</p>
<p>3. Farrell, M., Ryan, S., &amp; Langrick, B. (2001). 'Breaking bad news' within a paediatric setting: An evaluation report <i>Journal</i></p>	<p>Workshop. 34 Nurses, 10 Doctors</p>	<p>Any pediatric illness</p>	<p>To evaluate a workshop to prepare health professionals for breaking bad news in the paediatric setting.</p>	<p>Seven themes, including development of practice, the value of sharing, benefit of feedback, and teamwork, emerged from responses. All responses indicated that the workshop had been beneficial and an effective training method, with most participants (40 of 89%)</p>	<p>-Was only an evaluation of a training workshop for delivering bad news. -Study was written over ten years ago.</p>

<i>of Advanced Nursing, 36 (6): 765-75.</i>				indicating that it would be strongly recommended to colleagues to attend a similar workshop.	
4. Pirie, A. (2012). Pediatric palliative care communication: Resources for the clinical nurse specialist. <i>The Journal for Advanced Nursing Practice, 26 (4): 212-5.</i>	Literature Review	Palliative Care	The purpose of this study was to highlight the lack of communication skills pediatric practitioners have when delivering bad news and introducing pediatric palliative care to a family with a life-limiting condition	There are three phases of delivering bad news: Preparation, Delivering, and Planning. The study also mentioned that not enough research has been done on communicating with pediatric patients diagnosed, (and in this case) those who will go through palliative care.	-Literature review that talks more about what the nurse faces when delivering bad news as compared to how s/he should deliver the bad news. -Mainly references something the American Academy of Pediatrics and the World Health Organization published over ten years ago.

<p>5. Horwitz, N., &amp; Ellis, J. (2007). Paediatric SpRs' experiences of breaking bad news. <i>Child: Care, Health &amp; Development</i>, 33(5): 625-30.</p>	<p>Questionnaire-based survey  Physicians. N=206, 78 females and 34 males.</p>	<p>Down Syndrome</p>	<p>To ascertain the level of support and training available to paediatric specialist registrars (SpRs) in breaking bad news and self-reported confidence in this task.</p>	<p>This study took a different take on the matter. It asked qualified healthcare professionals about the thought of breaking bad news to families. It was found that even these healthcare professionals found that caregivers were dissatisfied in the way that news was related to them. The individuals who related the bad news were trained in doing so, but according to the caregivers, competence in doing so was not enough.</p>	<p>-Is a survey of the specialists who delivered the bad news, as compared to the caregivers or child who received the news. Thus, it can only be assumed what the caregivers or child want as compared to having quantitative data on this question.</p>
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<p>6. Ahmann, E. (1998). Review and commentary: Two studies regarding giving "bad news." <i>Pediatric Nursing, 24</i> (6): 554-6.</p>	<p>Review of two studies in which bad news was given</p>	<p>Chronic illness or disability</p>	<p>To compare two studies in which bad news was given</p>	<p>Both studies: It is important to: provide a private setting; many caregivers prefer someone familiar with the child to deliver the diagnosis, not an expert in the field; simple, direct language; give the caregivers positive aspects about the child and then negative information. In this study as well, the nurse's role is more of setting up the environment and giving family support during and after the diagnosis.</p>	<p>-Literature review, not quantitative data. -Review is on two studies written over 15 years ago.</p>
<p>7. Krahn, G.L., Hallum, A., &amp; Kime, C. (1993). Are there good ways to give 'Bad news'? <i>Pediatrics,</i></p>	<p>Interviewing the caregivers</p>	<p>Any disability</p>	<p>To find what the caregivers preferred when being told (for the first time) that the child has a disability</p>	<p>Caregivers were interviewed upon learning of the child's disability. It was found that caregivers appreciated straight-forward information (no "beating around the bush"), no medical terminology or negative portrayal ("many</p>	<p>-Small sample size (caregivers of 24 children) -Study was written over ten years ago. -Did not touch upon specifics of how to give bad news, such as words to avoid or use, etc.</p>

91(3): 578-82.				anomalies”), given by a single professional, empathetic approach, privacy during talk, and should be <i>in person</i> and not over the phone, another support person present (i.e. not just one person: mom and dad, or someone else), holding or touching the baby before or during interview (both pediatrician and family members), wanting information for support groups and another family who is going through something similar.	
8. Wright, J.A. (2008). Prenatal and postnatal diagnosis of infant disability: Breaking the	Any disability	Any disability	To define the role of the perinatal educator when news of a disability is being delivered to mothers.	When delivering bad news to a new mother, it is important not to diminish “the joy of birth.” The nurse should encourage the mother (in this case) to seek care and support; this is especially useful when finding a mother	-Literature review, not quantitative data. -Focuses more on perinatal education thereby making it less broad when it comes to age groups of children. -Focused on how to give

news to mothers. <i>Journal of Perinatal Education</i> , 17 (3): 27-32.				of another child with the same illness: has excellent bonding.	bad news to only the mother as compared to other members of a family.
9. Svavarsdottir, E.K., Tryggvadottir, G. B., & Sigurdardottir, A.O. (2012). Knowledge translation in family nursing: Does a short-term therapeutic conversation intervention benefit families of	Clinical trial using family interviews, 76 families	Acute and chronic illnesses	To evaluate the effectiveness of a short-term therapeutic conversation intervention with families who were receiving healthcare services at the Children's Hospital at Landspítali University Hospital in Iceland.	Although this study did not focus on the time of diagnosis, it still focused on the importance of therapeutic conversations with caregivers of a child with an acute or chronic condition. It was found that caregivers who got therapeutic conversation felt a lot more perceived cognitive support as compared to the control group ( $F = 6/742$ , $p = 0.011$ ), but not much more perceived emotional support ( $F = 1.74$ , $p = 0.074$ ). Caregivers of children with acute illnesses felt more	-Measures used were new and not previously evaluated in any other settings.

children and adolescents in a hospital setting? Findings from the Landspítali University Hospital Family Nursing implementation project. <i>Journal of Family Nursing</i> , 18 (3): 303-27.				cognitively supported ( $F = 7.433$ , $p = 0.003$ ) as compared to the control group.	
10. Skotko, B. (2005). Mothers of children with Down Syndrome reflect on their postnatal	Survey	2,945 people on Down Syndrome organization members	To document, in the most robust comprehensive way, the reflections of mothers in the United States whose children	Mothers think that physicians should emphasize the positive aspects of Down Syndrome ( $p < 0.001$ ), and not give statistics that do not pertain to the child. However, the doctor's way of delivering the diagnosis has improved a lot	-Risk of recall bias: the mothers received this survey at an average of 11 years after the diagnosis of Down Syndrome was disclosed. -Selection bias: only mothers part of a Down

support. <i>Pediatrics</i> , 115 (1): 64-77.		hip lists	received a diagnoses of DSs	since the 70s and 80s. Mothers liked preferred being told sooner (when the doctor suspected Down Syndrome) rather than later; mothers want a support person present with them. Mothers did not like it when doctors pitied or used negative language to describe the diagnosis. Finally, receiving written information is a must, as is being given the names of other caregivers with a child with DS (p = 0.0001).	Syndrome support group were given the survey, of which only 42.4% of people responded, suggesting that only mothers with difficult experiences answered the survey. -Because only those mothers enrolled in a support group were given the survey, certain socioeconomic and ethnic classes were not represented; for example, this study was completed mostly by middle to upper- class white females.
11. Sheets, K., Baty,B., Vázquez, J., Carey, J., & Hobson, W. (2012).	Semi-structured qualitative interviews. 14 mothers	Down Syndrome	To determine how to deliver bade news in a cross-cultural setting.	The mothers desired the news in a more positive, balanced light and with more complete explanations about the condition. Mothers felt excluded from the diagnostic	-Small sample size (n = 14). -Only mothers were included, not any other members of the family. -Focus was on Latina

<p>Breaking difficult news in a cross-cultural setting: A qualitative study about Latina mothers of children with Down Syndrome. <i>Journal of Genetic Counseling</i>, 21(4): 582-90.</p>				<p>process and wanted to be better informed about the need for diagnostic studies. 13 of the 14 mothers wanted the diagnosis before birth. Mothers needed a support person (mostly a spouses), did not like medical jargon, and wanted time with the doctors to ask questions.</p>	<p>mothers, thus decreasing the ethnic diversity of the participants.</p>
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## **Appendix B: 19 Identified Themes**

## Appendix B: 19 Identified Themes

1. Better explained diagnosis
2. Less medical jargon
3. Slower pace
4. Less negative information, more positive information regarding the child
5. Disclose the information ASAP
6. Provide privacy and disclose in a private setting with spousal support present
7. For physicians: No inaccurate information; present the information with the child present
8. Be empathetic
9. Let parents show feelings
10. Allocate a time to ask questions at the end
11. Give contact information of other families and support groups
12. Provide written and verbal information
13. Individualize to the family's situation
14. Healthcare professionals present should be familiar to the family
15. Provide a private room for the family after the disclosure
16. Incorporate the mother's views since the mother is the one who is usually with the child  
the most
17. Inform in the family's own language
18. First congratulate the family on the child's birth and then talk about the diagnosis
19. Do not give personal opinion

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