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# Examining Effective Provider~~atient~~-Parent~~rovider~~ Communication of Bad News~~when a young child is suspected of having a serious medical issue~~

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## Abstract

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This study ~~was configured to~~will examined patient-provider communication from a parent's perspective. Research shows communication between patients and providers to be important~~;~~, however ~~if~~ when a child is too young to understand their diagnosis, the parent ~~is left to make sense of i~~is often the focus of the patient-provider communication. Parents often report not having effective communication with their children's physicians, especially when the doctor shares bad news about the child's health. The need for effective communication becomes especially important when the provider must give the parents important information to help them make the best decisions about their child ~~t~~. This research project sought~~eeks~~ to understand what factors influence parental perceptions of effective communication by providers~~physicians~~ when giving bad news about a child's health. ~~This study will examine how the breaking of "bad news" effects a parent. If there is a link between empathetic providers and the credibility of those providers.~~

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Doctor's visits are not seen as a fun experience for anyone; there is often fear of what bad news may come from the appointment. When a parent takes their young child to a provider, many different types of fears enter their thoughts. Those fears can slowly become realities, as they did for Amy Markoff Johnson, who described her experience in an article for the *Huffington Post* (Johnson, 2012). She and her husband worried about their son's development because of his lack language abilities. They explained these worries to their son's pediatrician and received a statistic explaining that many children do not have comprehendible language until they have reached the age of two. Once her son reached his second birthday with no real progression on his language, a series of tests began. It wasn't until a year later that the term Autism was even mentioned; ~~, but~~ this was not a diagnosis, but the parents "should be prepared." After months of speech therapy, there was a lot of improvement within their child, however there were still "atypical behaviors" which caused concern. It wasn't until Amy's son turned four years old that a neurologist finally diagnosed him with Autism. Two and a half years of parental concern only resulted in the providers shying away from a diagnosis. The main communication message to the parents was to "prepare," but not giving an answer to their question: what is wrong with my son? (Johnson, 2012).

Unfortunately, similar stories of provider ~~physician~~ concerns and parental hesitations could be presented. ~~Overall,~~ T~~t~~here are serious communication issues in provider-parent communication that are ultimately delaying needed care for children. Hesitations are not the only communication issue. Parents are becoming increasingly aggravated with the ~~terminology~~ jargon used by providers~~physicians~~ to diagnose their children~~,~~ that is often offered with little to no explanation. Providers~~Physicians~~ ~~additionally~~ are not often trained to ~~becoming any more~~

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~~comfortable with~~ tell~~ing~~ ~~the~~ patients bad news (Barnett, 2004). The arguably most difficult thing to tell a patient is a 'bad' prognosis, especially in children, and yet there still isn't much training on how to tell patients this important information (Committee on Children with Disabilities, 2001). Additional research is needed to examine how parents and providers determine effective communication and ways to build the provider-parent relationship that allows for timely treatment for children.

## Physician and Parent Communication About Bad News

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Parents prefer open communication between their child's pediatrician and themselves. If they have open ~~communication~~communication, then they feel more likely to ask questions if there is any confusion. Provider~~Physician~~s must listen carefully to parental concerns so that they may address any issues early on. When a parent shows concern, the initial provider~~pediatrician~~ should attempt to address the direct concern immediately~~.~~ (Committee on Children with Disabilities, 2001).

Provider~~Physician~~s have avoided prognosis when they feel a ~~patient~~ parent may not know what is ahead. Although it may make the provider~~physician~~ uncomfortable, many parents report that have made it clear that they prefer to know about the prognosis to help create some sort of ease to their own thoughts. Many parents find being informed on their child's prognosis helps so they may decide upon the best route of care to take (Mack & Joffe, 2014). It is clear parents want to be informed no matter how difficult the news is to hear. The information, when thoroughly explained and understood, improves their since of hope (Mack & et al., 2006). ~~.~~

**Commented [A1]:** This is not necessarily true—there is research that shows parents will resist diagnosis of their children—especially in a disability context.

So, what you need to do in this section is qualify your statements—sometimes it's the physician who is the main problem, but sometimes it is parents who do not want the bad informatio

### Communicating 'Bad News'

If the delivery of bad news is done well and at the proper time, it can provide a mutual trust between the patient and physician, which is necessary for the possible long journey ahead

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together (Barnett, 2004). Unfortunately, there are many barriers to effective communication of bad news. Clinicians have hard time breaking down bad news to patients for several reasons. In a case where a patient is diagnosed with cancer the bad news sometimes comes in stages: initial diagnosis, treatment progression, and possible secondary spread (Source). When a providerphysician must deliver bad news, it is difficult for them because of their sense of failure, even if there was nothing the provider could have done to prevent the diagnosis. Another difficult issue is the agreement between providers on the diagnosis. If a patient should choose to get a second opinion and it differs from the initial diagnosis even slightly, doubt of both of the provider's' credibility comes forth. If the delivery of bad news is done well and at the proper time, it can provide a mutual trust between the patient and physician, which is necessary for the possible long journey ahead together. (Barnett, 2004)

Another major barrier to the effective delivery of bad news is the emotional processing of the patient. Bad news is rarely accepted when first hearing it (Morse, 2011). Medical providers need to be more prepared when a parent has disbelief of the diagnosis (Fallowfield, 2004). Many patients are not prepared to hear the information that they need to know. Setting the tone of the discussion by giving the parent options to bring emotional support with them is important.

**Physicians Communicating Bad News to Parents**

Research has identified best practices for providers communicating with parents. Pacing the conversation when giving the initial diagnosis is key to helping the parents understand the depths of their child's health. Giving clear, simple language at the first diagnosis helps parents to absorb the news fully (Barnett, 2004). Most of the time a physician's emotional support level when explaining negative news can create a less stressful outcome for the parents (Gemmiti, 2016). However, that is not always the case. Sugar coating a diagnosis may seem more humane,

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~~but~~humane but is not seen as a desirable method to many parents (Sices, 2009). Parents find the time of which they are given the diagnosis of their child to be crucial. The parents and children express a lack of trust when a pediatrician is calling for testing and not explaining the reasoning behind it (Konstantynowicz, 2016).

Parents too often are not feeling as if they are being heard when voicing concerns on their child's developmental rate. Physicians giving a scripted answer to these concerns causes the parent to feel they are justified in blaming the physician for not catching their child's diagnosis earlier on (Committee on Children with Disabilities, 2001). Timing is crucial with diagnosing children. Early intervention is known to help the outcome of the child's life. Giving bad news to patients doesn't have to be a scary thing (Krahn, 1993). Knowing the full prognosis of their child in plain and simple language to its full extent has helped parents to feel a sense of hope even though there isn't much they can do (Mack, 2014).

**Effective Provider-Patient-Child Communication**

Providers' attempt to try to answer all a parent's questions in a closed question format of yes and no answers causes parents to feel the provider lacks any interpersonal interest in the family's well-being. Northwestern University recognized this issue amongst providers' bad news delivery and developed a communication program center around the proper technique to deliver negatively perceived news. The American Academy in Communication in Health Care (AACH) also designed intensive training modules on communication to improve residential skills when describing to a parent how their child's lifelong disability developed (Levetown, 2008).

After taking these classes providers' have shown improvement in their approach to communication. Connecting with the parents in a concise and understanding manner helps

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parents to be a part of their child's impending health decisions. Time spent to learn how to express interpersonal sensitivity with patients has long term benefits such as greater patient outcome and satisfaction as well as professional achievement. If the parents feel as if the provider is uninterested during the consultation then the parent may reveal less to the provider causing sometimes no further action on the child's health to be taken (Levetown, 2008). Parents want communication to be informative, interpersonally sensitive, and partnership building.

The empathetic nature of providers creates an open discussion environment (Sices, 2009). If a provider shows a lack of sensitivity to the severity of the situation with a pessimistic outlook parents become more hostile (Krahn, 1993). ~~A n givegives one paragraph to the importance of expressing empathy, one on physician credibility, and one on how physicians can help persuade parents to take further actions to help their children.~~

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**Synthesis Section**

Most medical schools offer little training on effective communication strategies. Because of their training, most providers~~hysicians~~ tend to focus on providing information to their patients and are often not as concerned with interpersonal sensitivity. The lack of interpersonal dynamics often leads patients to feel misunderstood and devalued by their medical providers. Overall, more patient-centered communication is needed; this is especially true for providers~~hysicians~~ working with parents of young children.

A myriad of communication strategies are currently used by providers~~hysicians~~ when giving parents of young children bad news. Whereas some providers~~hysicians~~ adopt a straightforward informative style, others ~~physicians~~ try to adopt very positive eaffective tones to lessen the severity of the information. The language and communication style that

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providershysicians use when communicating with parents can shape the families' understanding of the situation and decision--making process. Therefore, it is vital for health communication research to provide guidance on what strategies may be effective for providershysicians. Currently, the literature has mixed findings on the role of provider'sphysician emotion in parent's ability to process the information provided and their overall satisfaction of the healthcare provided.- In particularOverall, research indicates that parental satisfaction with their child's healthcare will be positively correlated with perceived interpersonal sensitivity of their providerhysician; but this claim needs further testing. Therefore, the following hypotheses are proffered:

H1: Perceived empathy of the providerhysician will be positively correlated with the providerhysician's perceived credibility.

H2: Parental satisfaction with the communication of bad news will be positively correlated with perceived empathy of their providerhysician.

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## Method

### Participants

The population of interest were~~is~~ parents who have a child under the age of 18 ~~105~~. A convenience sample will be recruited via a snowball technique. The solicitation message ~~will~~ requested participation from parents who have a child that was diagnosed u~~atchildren, under the age of ten or u~~nder the age of eighteen~~five and~~ who have received any type of information ~~they~~ would classify as "bad news" about their child from their care provider. The researcher hopes to recruit at least 3~~5~~0 participants ~~will be recruited~~ to complete the study. The survey asked~~will ask~~ demographics such as their age, race~~, ethnicity, number of children~~, income, and educational background.

### Procedures

The study was~~will be~~ conducted via an online survey through Qualtrics. The survey link w~~as~~ill be sent out to parental organizations that focus on irreversible medical conditions ~~childhood disabilities~~a ~~a~~nd illnesses ~~in this area~~ with a request for participation in the survey. The survey link was ~~will also be~~ posted on social media with a request for participation. Participants were ~~will~~ first ~~be~~ asked to ~~click on the survey link and~~ provide consent to participate in the study. They were ~~will~~ then ~~be~~ asked to recall the doctor's visit when they were first given a diagnosis of "bad news" about their child's condition. Bad news was~~will be~~ defined as information that is unpleasant or negatively perceived. The participants were~~y will~~ then ~~be~~ asked to recall how the provider spoke~~talked~~ and behaved during that conversation by responding to scales that measure provider empathy, provider credibility, and patient satisfaction. This~~hey~~ w~~ill~~ theas~~n be~~ followed by a ~~asked a~~ series of questions about their demographics and information about their child's age and health status as well as the provider's medical title (psychologist, pediatrician, etc.).~~s. They will then be asked to recall the doctor's visit when they~~

Commented [A2]: Need to look at other research that is similar and look at what/how they measured things like the child's condition and age at diagnosis and maybe the type of doctor it was. The doctor's sex and info about the doctor.

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~~were first given bad news about their child's condition. Bad news will be defined as information that is unpleasant or negatively perceived. They will then be asked to recall how the physician talked and behaved during that conversation by responding to scales that measure physician empathy and physician credibility.~~ Finally, they were~~ill be~~ asked to indicate their overall satisfaction with the provider~~hysician~~'s delivery of bad news by leaving a comment.~~s.~~ Thereafter, parents will be thanked for their time and participation.

**Instrumentation**

**Perceived Empathy**

Perceived empathy of providers to parents. Perceived empathy was~~ill be~~ measured using a 5-item, 7-point Likert scale previously used in the Jefferson Scale of Patient Perceptions of Physician Empathy (Hojat, 2010). ~~One signifies strong disagreement.~~ Participants ware~~re~~ asked to indicate their feelings, emotions and concerns; how well they understoo~~an~~d; the level of concern from the doctor, and if the doctor could~~an~~ view the person's perspective.

**Perceived Credibility**

Perceived credibility of providers to parents. Perceptions of credibility will be measured by the generalized belief scale (Paulsel, 2006). This is a 6-item, 7-point Likert scale ~~where 7 indicated strong agreement~~. Participants are asked to indicate the assertiveness, responsiveness, immediacy, competence, care level, and how confidential they feel their provider~~hysician~~ is.

**Patient Satisfaction**.

Patient satisfaction was measured with a 7 item, 7-point Likert scale~~, where 1 indicated strong disagreement and 7 indicated strong agreement~~. Participants were asked to respond to

questions about the ability of the ~~proivder~~provider~~physician~~ to reassure them, the provider~~physician~~'s ability to explain the treatment, the quality of the information received, the feeling of security during the appointment, the extent of which the treatment plan was tailored to the child, the treatment overall, and their willingness to recommend the provider~~hysician~~ to families in similar circumstances. Parent's then will be given the opportunity to write in any additional comments about their feelings on the journey to diagnosis.

## Appendix

**Which of the following developmental disabilities has your child been diagnosed with? Please check all that apply.**

- Autism or ASD
- Intellectual Disability
- Neurological Disability
- Vision Impairment
- Hearing Impairment
- Sensory Impairment
- Genetic or Chromosomal Condition
- Other (Please specify)

**At what age was your child diagnosed?**

Birth-0-1-2-3-4-5-6-7-8-9-10-11-12-13-14-15-16-17-18

**What type of healthcare provider diagnosed your child's developmental disability?**

- Developmental Pediatrician
- Specialist
- Primary Physician or Pediatrician
- Psychologist
- OBGYN

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**Think about when your child was first diagnosed and your experience with the provider/doctor who diagnosed them. Respond to each of these statements about the provider/doctor who diagnosed your child.**

- My doctor understood my emotions, feelings, concerns.
- My doctor was an understanding doctor
- My doctor seemed concerned about me and my family.
- My doctor asked about what was happening in my daily life.
- My doctor could view things from my perspective (sees things as I saw them).

**Rank each word with your perception of the provider at the time of your child's diagnosis.**

- The provider was assertive.
- The provider was responsive.
- The provider was comforting.
- The provider was competent.
- The provider was caring.
- The provider respected our confidentiality.

**Continuing to think about when your child was first diagnosed, please rank each statement from strongly disagree to strongly agree.**

- The physician demonstrated an ability to put you at ease and reassure you.
- The physician's information received about treatment was satisfactory.
- The quality of information received about treatment was satisfactory.
- You felt confident in the physician's ability.
- You believed the treatment plan was adapted to your child appropriately.
- Your experience with the physician was overall positive.
- You would recommend this physician to families in similar circumstances.

**Please share your overall perceptions and feelings about the provider who diagnosed your child. Include recommendations for what you believe would have made your provider a more effective communicator.**

**What is your gender?**

- Male
- Female
- Prefer not to answer
-

**What is your age?**

- 18-25
- 26-323~~3~~
- 33-4034~~-41~~

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- 41-50
- 51-60
- 61-70
- 71-80
- 81-90
- 91-10048
- Over 100

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**Are you currently…?**

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- Employed for wages
- Self-employed
- Out of work and looking for work
- Out of work but not currently looking for work
- A homemaker
- A student
- Retired
- Unable to work

**What is the highest level of school you have completed?**

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- Some high school, no diploma
- High school graduate, diploma or equivalent (GED)
- Some college
- Trade/technical/vocational training
- Associate degree
- Bachelor's degree
- Master's degree
- Doctorate

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- ~~**48 years or older**~~

**Please specify your ethnicity or race.**

- African American
- Asian
- Caucasian
- Hispanic or Latino
- Native American
- Pacific Islander
- ~~O~~Other

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~~What is the highest level of school you have completed~~

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- ~~Some high school, no diploma~~
- ~~High school graduate, diploma or equivalent (GED)~~
- ~~Some college~~
- ~~Trade/technical/vocational training~~
- ~~Associate degree~~
- ~~Bachelor degree~~
- ~~Master's degree~~
- ~~Doctorate degree~~

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~~Are you currently…?~~

- ~~Employed for wages~~
- ~~Self-employed~~
- ~~Out of work and looking for work~~
- ~~Out of work but not currently looking for work~~
- ~~A homemaker~~
- ~~A student~~
- ~~Retired~~
- ~~Unable to work~~

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**What is your marital status?**

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- Single
- Married or domestic partnership
- Widowed
- Divorced
- Separated
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**What is your annual household income before taxes?**

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- Less than $1~~0~~,000
- $1~~0~~,00~~0~~ to $2~~0~~,000
- $2~~0~~,00~~0~~ to $4~~0~~30,000
- $4~~0~~30,00~~0~~ to $55,000~~39,999~~
- $55~~40~~,00~~0~~ to $65~~49~~,000~~999~~
- $65~~50~~,00~~0~~ to $75,000~~59,999~~
- $75~~60~~,00~~0~~ to $85,000~~$69,999~~
- $85~~70~~,00~~0~~ to $95,000~~79,999~~
- $95~~80~~,00~~0~~ to $105,000~~89,999~~
- $105~~90~~,00~~0~~ to $150,000~~99,999~~
- ~~$100,000 to $149,999~~
- $150,000 or more

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## Results

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The first hypothesis predicted that perceived empathy of the provider would be positively correlated with the provider's perceived credibility. Results of the bivariate correlation test indicated that empathy was significantly and positively correlated with credibility, $r(33) = .73$, $p < .001$. Hypothesis 1 was confirmed.

The second hypothesis predicted that parental satisfaction with the communication of bad news would be positively correlated with perceived empathy of the provider. Results of the bivariate correlation test indicated that parental satisfaction was significantly and positively correlated with empathy, $r(30) = .697$, $p < .001$. Hypothesis 2 was confirmed.

Further analysis of the variables in this study and the comments provided by the parents yielded some unexpected and interesting findings. Comment of the parents showed multiple parent's felt more secure with their pediatrician diagnosing their child even though they are not trained to do diagnostics of developmental disabilities.

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~~**Perceived Empathy**~~

~~Rank each statement from 1-7, 1 being strongly disagree, 7 being strongly agree.~~

~~1. My doctor understands my emotions, feelings, concerns.~~

~~2. My doctor is an understanding doctor~~

~~3. My doctor seems concerned about me and my family.~~

~~4. My doctor asks about what is happening in my daily life.~~

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~~5. My doctor can view things from my perspective (sees things as I see them).~~

~~**Perceived Credibility**~~

~~**Rank each word with your perception of the provider with 1 being strongly disagree to 7 being strongly agree.**~~

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~~1. Assertiveness~~

~~2. Responsiveness~~

~~3. Immediacy~~

~~4. Competence~~

~~5. Caring~~

~~6. Confidentiality~~

~~**Satisfaction**~~

~~Rank each statement 1-7, 1 being strongly disagree to 7 being strongly agree:~~

~~1. The physician demonstrated an ability to put you at ease and reassure you.~~

~~2. The physician's explanations about treatment were satisfactory.~~

~~3. The quality of information received about treatment was satisfactory.~~

~~4. You felt confident in the physician's ability.~~

~~5. You believed the treatment plan was adapted to your child appropriately.~~

~~6. Your experience with the physician was overall positive.~~

~~7. You would recommend this physician to families in similar circumstances.~~

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| Research Proposal Rubric | Points Possible | Points Earned |
|---|---|---|
| **Introduction/Rationale Section**<br>Report contains a clear statement of purpose that identifies the specific area of research literature that will be reviewed. Reasoning and evidence provided for examining the problem. | 10 | |
| **Literature Review**<br>The research referenced is complete and well suited to address the stated purpose of the research project. The author effectively extracted relevant data from the study's findings, organized it, and related it to the specific purpose of the research report. A minimum of 10 peer-reviewed sources are cited (other types of sources are also encouraged). | 25 | |
| **Hypotheses or Research Questions**<br>At least two high-quality research questions or hypotheses are proposed. (10 points per hypotheses or RQ) | 20 | |
| **Sample Section**<br>Population and how you will sample are explicitly stated. Human subjects or the artifacts being sampled for this study are explicitly discussed. Criteria for inclusion are mentioned. A minimum number of people/artifacts is mentioned and a justification is provided. Characteristics relevant to the sample that will be measured are also listed. | 10 | |
| **Procedures Section**<br>The methodology is explicitly mentioned. Step-by-step instructions of how the study will operate are written out. I could replicate your study by reading through this section. | 10 | |
| **Instrumentation Section**<br>All the measures for the study each have their own paragraph description. There is an explicit explanation of mention how everything will be measured. Sources for measures are internally cited. | 20 | |
| **Measures in the Appendix**<br>All of the measures are included in the appendix. You will either create a codebook, survey, or experimental induction with a questionnaire. | 25 | |

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| **Citations & References**<br>Everything cited within the report is provided in the references section. You have a minimum of 10 PEER REVIEWED JOURNAL ARTICLES CITED. You will lose -1 point for each reference not cited. | 10 | |
| **APA Style & Formatting**<br>The proposal follows APA format. A title page and abstract are included. The page formatting is precise. The references are correctly cited within the text and in the references section. | 10 | |
| **Professionalism**<br>The writing demonstrates that close attention was given to the accuracy and clarity of the proposal. It is free of typos and grammatically correct. The writing is clear and precise. | 10 | |
| **Optional- Writing Center Credit (15 points)**<br>Your proposal's final grade can be increased by 10% (15 points) with documentation that proves you had a Writing Center consultation about the proposal between 11/30 and 12/7. Please include documentation at the end of the proposal. | | |
| **TOTAL** | **150** | |