

An Examination of Physician-Patient Communication in Context of a Spina Bifida Diagnosis

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As a result of pregnancy, patients have increased contact with a physician. To complicate matters, learning that an unborn child will be born with an expected disability can increase the number of medical consultations. In this qualitative study, 23 participants were interviewed to describe and explain physician-patient communication in context of learning that a child would be born with an expected disability. Findings suggest patients perceived various forms of information exchange along with experiences in relational communication. Implications for physicians and patients are discussed.

Keywords: physician-patient communication, spina bifida, information exchange, and relational communication

Pregnancy is often characterized with joy. However, pregnancy often leads to feelings of anxiety, tension, uncertainty, and stress (Dragonas & Chistodoulou, 1998; Elsenbruch, Benson, Rucke, & Dudenhausen, 2007; Sjostrom, Langius-Eklof, & Hjertberg, 2004). As a result of pregnancy, patients have increased contact with a physician. Therefore, additional information regarding the medical process should be provided to patients during pregnancy (Aaronson, Mural, & Pfoutz, 1988). As Lambert and Loiselle (2007) noted, pregnant patient's information needs vary, and can range from a basic desire to understand a physician's decision to being an active participant in the decision making process. To complicate matters, learning that an unborn child will be born with an expected disability can increase the number of medical consultations given the disability's nature. Spina bifida, which is characterized as a condition that affects the spinal cord and nerves due to a backbone malformation (Spina Bifida Association, 2015), is typically diagnosed during pregnancy. Spina bifida is commonly associated with physical and/or cognitive disabilities.

Physician-patient communication is well documented by researchers (see Bell, 2007; Cegala, 1997; Rabow & McPhee, 1999; Street & Wiemann, 1988; Thompson & Parrott, 2002). Both content and style of physician-patient communication is important in the overall medical experience (Davis, 2010). However, it's important to note that communication is bound by context, and the physician-patient relationship is no exception (Avtgis & Polack, 2007). While research has focused on physician-patient communication, to our knowledge, research has not examined specific discussions in relation to an unborn child and a spina bifida diagnosis. In accordance with Avtgis and Polack (2007), "research should continue to explain the contextual factors surrounding the medical encounter to better explain the patient/physician relationship" (p. 137). Specifically, research should expand to understand physician-patient communication during the pregnancy of an unborn child who has been diagnosed with an expected disability.

The purpose of the current study was to address physician-patient communication in the context of an initial diagnosis and discussion of a child that would be born with spina bifida. By utilizing in-depth qualitative interviews, this study describes and explains the patient's perception of the communication exchange by physicians upon learning that their unborn child had spina bifida. What follows is an examination of literature related to physician-patient communication, which provides context to the current study. Specifically, the literature is focused on informational exchange and relational communication, which are important concepts in the medical encounter for patients as they learn of a spina bifida diagnosis. The literature review is followed by a description of the qualitative methodology. The findings section provides the themes generated from data analysis. Finally, implications for physicians and patients are discussed.

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Physician-Patient Communication

Thompson and Parrott (2002) noted how “communication skills” rather than “communication competence” has been a focus of physician-patient communication in the medical profession. For instance, Rao, Anderson, Inui, and Frankel (2007) stated effective communication skills are the foundation of patient-centered care. Pendleton’s (1983) research noted physician-patient communication requires good listening skills along with the physician clearly communicating information to the patient. Argyle (1983) noted how physicians must consistently work with patients, and “technical knowledge and skills are required, but this cannot be used unless the practitioner is able to communicate, persuade and generally deal with his clients” (p. 57). Many research articles offered by medical practitioners provide tips to train physicians and nurses in regards to best communication practices (see Argyle, 1983; Hulsman, Ros, Winnubst, & Bensing, 1999; Lechner, Sheilds, Tucker, & Bender, 2015; Rabow & McPhee, 1999). Furthermore, Lechner et al. (2016) noted upon delivering bad news related to a diagnosis, physicians should be trained to effectively communicate with a patient. However, training is lacking (Lechner et al., 2016; Rabow & McPhee, 1999).

Street and Wiemann (1988) noted the uniqueness of the physician-patient relationship, which is entrenched in personal elements of self-disclosure and access to the body while at the same time approached with professional and formal communication. Given this context, research indicates that effective physician-patient communication is critical in providing a perception of a likable, involved, and concerned physician (Bell, 2007; Pendleton, 1983). Additionally, clear communication is critical in developing greater patient satisfaction with the information received (Burgoon et al., 1987; Hoffman & Del Mar, 2014; Luff et al., 2016). Parents typically learn of a spina bifida diagnosis during pregnancy, which increases the amount of consultations with a physician. Therefore, a spina bifida diagnosis provides a unique context to explore the physician-patient communication experience. There are two aspects of physician-patient communication that has been given consistent attention by researchers: information exchange and relational communication. Both are described below.

Information Exchange

Researchers have noted the fact that the primary goal of communication during a medical consultation is the exchange of information between a physician and patient (Beisecker & Beisecker, 1990; Frederikson, 1993; Guttman, 1993; Thompson & Parrott, 2002). Cegala (1997) stated, “effective doctor-patient communication, in part, involves information exchange about such matters as medical history, symptoms, diagnosis, and prescribed treatment” (p. 170). DiMatteo, Reiter, and Gambone, (1994) stated, “in general, patients prefer far more detailed disclosure than their physicians routinely offer them, and patients want far more information than they tend to ask for” (p. 256). To emphasize the importance of information exchange in the medical encounter, research demonstrates the point that information exchange is of more importance than social support for the seriously ill (Hinds & Moyer, 1997). Furthermore, Orioles, Miller, Kersun, Ingram, and Morrison (2013) concluded that physicians should repeat information and provide opportunities for questions repeatedly with a patient during informational exchange, especially when delivering an unfavorable diagnosis. Emphasizing the importance of information exchange, Oshea et al. (2007) discovered the fact that parents appreciated when a physician took an opportunity to repeat information related to a leukemia diagnosis for a child.

Beisecker (1990) detailed a variety of factors that affect the communication exchange between the physician-patient encounter, which include patient attitudes, situations, and sociodemographic factors, such as age, gender, income, education, and cultural background. Pendleton (1983) stated the idea that physician communication is important as it is deeply connected to the level of satisfaction a patient has with the information exchanged during a medical consultation. Orioles et al. (2013) noted how the lack of thoroughness in relating information causes frustration and distrust for patients. VanDulmen and Bensing (2002) stated benefits, such as improvement in recovery and reduction of stress, is gained from gathering good information. Thompson and Parrott (2002) pointed out how interpersonal communication impacts a variety of items, from the reception of a diagnosis to following physician proscribed treatments.

One area of information exchange between physicians and patients is the medical interview. Cegala (1997) noted three components of information exchange in a medical interview: (1) information-seeking is the process of gathering information during a medical interview, (2) information-giving is focused on self-disclosing information

to another, (3) and information-verifying consists of relevant questions and restatements that help both parties to better understand the information exchanged. Furthermore, Street (1991) discovered the fact that patients ask more questions regarding treatment while physicians ask more questions to understand a diagnosis. In context to the current study, understanding the information exchange process in the medical encounter is important to understand the experience a parent goes through when learning of a spina bifida diagnosis.

Relational Communication Among the Physician-Patient Relationship

As O'Hair (1989) noted, "we define the nature of the relationship through our communication" (p. 99), and the physician-patient relationship can be viewed through a relational communication lens. Considerable attention has focused on the communication exchange between physician and patient in regards to building rapport and providing emotional support (Bensing, 1991; Orioles et al., 2013; Suchman & Matthews, 1988; VanDulmen & Bensing, 2002). VanDulmen and Bensing (2002) referred to relational communication in the physician-patient encounter as an exercise in interpersonal communication where verbal and nonverbal messages build rapport and trust, develop emotional support and empathy, and ease a patient into the experience. O'Hair (1989) pointed out three dimensions of relational communication that directly relate to the physician-patient relationship: (1) control, (2) trust, and (3) intimacy. Likewise, research describes a physician's use of empathy as critical in building trust with a patient when delivering bad news regarding a child's medical diagnosis (Bell, 2007; Orioles et al., 2013).

Kreps (1988) demonstrates how patients' satisfaction correlates to the medical encounter based on a physicians' relational communication. Dissatisfaction is linked to limited feedback, insensitivity, lack of empathy, and decision-making inputs (Kreps, 1988). In a focus on relational communication, Burgoon et al. (1987) discovered that immediacy, composure, similarity, receptivity, and formality along with less dominance by a physician yielded greater patient satisfaction. Additionally, relational communication demonstrated a connection to the compliance by a patient (Burgoon et al., 1987).

Research demonstrates the need for informational exchange and relational communication in the physician-patient experience (Bell, 2007; Cegala, 1997; Orioles et al., 2013; Thompson & Parrott, 2002). Although studies have explored these concepts, research should be expanded to incorporate the experience of communication exchange in context to a spina bifida diagnosis. The following research questions guided the study:

RQ1: How do patients experience communication with their physician upon an initial spina bifida diagnosis of their child?

RQ2: To what extent do patients experience informational exchange during physician-patient communication upon an initial spina bifida diagnosis?

RQ3: To what extent do patients perceive relational communication from interactions with a physician upon an initial spina bifida diagnosis?

Methodology

The current qualitative study was conducted as part of a larger study exploring spina bifida diagnosis and communication. To focus the study, in-depth qualitative interviews were used to explore a real-life phenomenon (Merriam, 1998; Yin, 2009). More specifically, a qualitative interviewing approach provided insight, discovery, and interpretation into the physician-patient communication process. Qualitative interviews were helpful because the research was limited to a specific group of people who were involved in a specific spina bifida discussion during pregnancy.

Participants

Once Institutional Review Board approval was obtained, we recruited participants using a purposeful sampling technique, which allows a researcher to identify a sample that has certain characteristics that allows for in-depth, detailed information about specific cases to select participants (Patton, 1980). We recruited 23 women who were pregnant in which the unborn child was diagnosed with spina bifida. The first author interviewed all

participants. Since the purpose of this study was not to generalize the findings to other settings but to provide insight, discovery, and interpretation of the physician-patient communication in the context of learning that a child would be born with an expected disability, the 23 participants provided ample information to garner an in-depth understanding of the communication process and allowed identifiable themes to emerge from the data.

Recruitment began with connecting to participants known by the first author (n=5). These participants provided additional recruits through a snowballing technique (n=8), which was useful to find interviewees who were socially networked to the researcher's initial contact (Warren & Karner, 2010). Finally, additional recruitment of participants was aided by calls on social media outlets and through regional and state spina bifida associations (n=10). Interviews were conducted until we were able to generate major themes. Throughout the participant selection and interview process, we maintained the confidentiality of all participants by referring to participants by a pseudonym. As a result, the findings present all participants by their pseudonym.

Although the age of participants varied, the mean age of participants was 35 years old. We did not find that the descriptive data varied based on age. All participants were interviewed after the child was born. Therefore, the median age of the child that was born with spina bifida was three years. The children ranged in age from 3 months to 19 years old. The participants consisted of 15 Caucasians, two African Americans, three Native Americans, one East Indian, one Filipino, and one Hispanic.

Interview Procedure

The interview period lasted 6 months, from August 3, 2015 to January 3, 2016. Interviews were conducted in person (n=5) or over the phone with each participant (n= 18). The average interview length was 51.54 minutes, with the shortest interview ending at 36 minutes and the longest lasting 87 minutes. To capture the data, the first author utilized a digital audio recorder. Prior to beginning the interview, all participants provided informed consent. The first author followed a semi-structured protocol consisting of questions that related to physician-patient communication, initial spina bifida diagnosis, communication suggestions for physicians delivering a spina bifida diagnosis, and diagnosis disclosure with others. Additionally, the open-ended nature of the semi-structured protocol, along with the relevant conversation with each participant, allowed for additional questions and conversations regarding the pregnancy, and how spina bifida was discussed with the physician.

Data Analysis

Following the suggestions by Sunstein and Chiseri-Strater (2007), interviews were accurately transcribed after each interview by reviewing the audio recordings and typing sentence by sentence the responses made by participants. Data consisted of 235 pages of transcriptions. Once transcriptions were made, we began to code the data. Glaser and Strauss (1967) noted coding data provides a means of categorizing narratives by themes, either by the language or general data from the interviews, which allows a comparison to evolve into an emerging property for each theme.

We analyzed the data through the constant-comparative method following two systematic steps. First, we open coded interview data by reading each transcript and making notations, comments, and notes in each transcript margins. Open coding provided us with a brief description of data that was possibly relevant or essential to the study.

During the second stage we engaged in axial coding, also known as theme construction, which allowed us to reflect on the meanings of the emergent themes. In this step, we reviewed the notations and comments from stage one of open coding and grouped comments and notations that were similar or naturally fit together. As a corollary of stage one, we generated several major themes. At the end of this stage, themes captured a pattern across all of the data that were able to answer the study's research questions.

Finally, we kept an audit trail of all the raw data collected within the study along with a detailed description of the steps followed in the analysis. Lincoln and Guba (1985) noted that the audit trail allows an outside researcher to metaphorically audit both the research process and product to attest to the study's dependability. We enlisted the help of a colleague who engages in qualitative research to conduct an audit of our findings. She verified that the conclusions drawn from the coding process were accurate and reflected the themes and categories derived from the interview data.

Findings

All participants in this study explicitly described the experience of physician-patient communication as an application of information exchange. In relation to information exchange, the participants described three distinct categories: (1) open acknowledgement of the lack of information regarding spina bifida, (2) patients were information-seekers, and (3) specialists provided a thorough exchange of information. Participants also described deep experiences in relational communication during the physician-patient medical encounter. In regards to relational communication, participants identified two distinct categories: (1) insensitivity upon initial diagnosis, and (2) a variety of relational approaches. Detailed results are listed below.

Lacking Information Acknowledgement

This subcategory of informational exchange establishes that a patient's primary OBGYN physician directly told participants that he/she was not a specialist, and lacked the information necessary to provide details about the spina bifida diagnosis. In this subcategory, physicians owned up to the fact that a specialist would be better equipped to handle the remainder of the pregnancy due to the unborn child's spina bifida diagnosis. For instance, Abby stated:

He didn't want to tell anything about it [spina bifida] that set an expectation that could not have been met. It made me realize that he is just an OBGYN. He couldn't even say whether the baby is going to live. That was outside of his specialty so he couldn't comment on it what could potentially set an expectation. He was wasn't really able to provide any information so thankfully within two hours we were able to get to a specialist who gave us more information.

Shanna reinforced this sentiment regarding her OBGYN by stating, "What I have learned since then the people that are your regular OBGYN type of person, they get maybe 30 minutes in their career or one paragraph about spina bifida, and that's it."

The data suggests that participants appreciated and desire honest information exchange, even when a diagnosis is outside of the physician's specialty. Stephanie stated, "She said, 'Well, I am going to get you the best doctor I know cause I don't know how to deal with this.'" By honestly exchanging with patients that spina bifida was not common under his/her practice, participants were provided a frame of reference for the necessity of seeing a specialist.

In contrast, six participants noted that they were given inaccurate information by their primary OBGYN upon initial diagnosis. Kristen stated:

We were told essentially that she had the worst kind of spina bifida, and it was very severe, even in terms of what he's seen over his career. And we should expect her to be completely paralyzed from the hips down and very likely have brain damage. That's the expectation that he laid out there for us of what was going to happen. He was really wrong. I personally do appreciate the like, blunt kind of approach. But I just want the person to only say what is accurate and then, like, don't give me a spiel that you read in your medical textbook 25 years ago from one paragraph on spina bifida that you read in medical school. That is not okay.

In general, participants felt physicians should provide informational exchange within the medical encounter, but also be honest with a patient when a diagnosis is outside the boundaries of the physician, which results in the need for the patient to see a specialist.

Information-Seekers

Participants explained this subcategory of information exchange as being active participants in the medical encounter. Participants actively asked questions seeking additional information regarding spina bifida and quality of life, and the action steps needed to continue the pregnancy. Upon the initial diagnosis, Jessica said:

I had no idea what it was. Initially my husband broke down in tears and I started asking questions. Well what is that? Is there anything to do in utero? Is he going to be able to walk? Those kind of questions. I

asked as many questions as I could right then to get our minds around it because we did not know what it was.

Asking questions allowed participants an opportunity to allow physicians to communicate information about the diagnosis and how to proceed. As a result, information-seeking techniques allowed participants to better understand spina bifida. Isha offered, “She told me if I had any questions I was to ask her and she’d get me the answer and then I would and she would tell me. Which is exactly what I did because she’s been very supportive.”

In regards to taking action, Kim stated, “One of the first people I called was the specialist. I wanted to know how quickly I could come in.” As a result, participants described that asking questions was the first time they began to advocate on their child’s behalf.

Thorough Exchange of Information

The final subcategory of the information exchange theme related to the amount of honest, detailed information that was communicated from specialists to patients. In general, participants noted that unlike the initial diagnosis by their primary OBGYN, specialists communicated detailed information and expectancies regarding their child and spina bifida. Shanna described the first conversation with her specialist as follows:

He sat down and he had a piece of paper on his lap. He had written down a couple of words. He walked through the different parts of her body and what he had seen and he wrote down the terms for it. Walked through here’s what we are seeing with her brain. Here’s what we are seeing with her spine. We’re seeing spina bifida. He walked through all of that. Her feet and her hands. Her feet looked very normal. A lot of the times we do see clubbed feet with this but we don’t see it with your daughter. We were like “okay.” I remember we listened a lot and he was writing things down and it turned out to be incredibly helpful.

In contrast, several participants noted that specialists lacked detail in providing initial explanations or were too blunt with the descriptions upon the initial diagnosis. For instance, Kim stated, “The specialists we were referred to, they were not helpful because their discussions were very black and white.” These contrary statements stress the importance of being patient-centered in terms of physician-patient communication.

Other participants described being overwhelmed with the amount of information provided by specialists. Joy offered, “The initial consultation was really overwhelming. It was 2 days, and an MRI. We met the neurosurgeon. A neurologist talked to us, and we were sent a social worker. They sent all of these people down and it was overwhelming.”

Finally, participants noted the use of caseworkers, genetic counselors, and social workers that provided detailed information. Visiting with these professionals provided additional information and, in some cases, participants noted they were less intimidated to talk with them. As a result, the specialists were able to bring normalcy of the pregnancy back to participants. Molly explained:

They had a lady kind of assigned to us that would come meet us and would explain each of the providers. She would make sure we were okay, and give us snacks. That was really nice just to kind of have someone who wasn’t so intimidating. She was super familiar with the process of spina bifada, but, you know, we didn’t feel so intimidated by her so we even asked her some questions that she was like “Let me call so and so” and she would call the doctor or whatever and kind of fill in some gaps and things we forgot to ask or whatever. That was really good. I felt really good about the whole day and process of that and finding out more about spina bifida.

The subcategories of acknowledging a lack of information, seeking information, and providing thorough details about spina bifida serve as information exchange purposes in the context of physician-patient communication. What follows is an explanation of the relational communication aspects of the medical encounter for pregnant women learning of a child’s spina bifida diagnosis.

Insensitivity

Eleven participants described and explained how a physician relayed the initial spina bifida diagnosis with an insensitive approach. This subcategory of relational communication highlighted the different verbal and nonverbal messages sent by physicians who were received as insensitive by the patient, which addresses the need for physicians to not only consider the message said to patients upon revealing a spina bifida diagnosis, but also the delicate balance of how the diagnosis is delivered. Kim described asking questions about the diagnosis with her physician as follows: “Do you think she will be able to walk? He laughed at us, and said ‘that is not something I can tell you. It is not that obvious.’ I was like, oh my gosh, how insensitive.” Participants frequently mentioned verbal and nonverbal messages as cold and distant, not helpful, too blunt, and that they felt as though they were just another number. For instance, Shanna shared the following encounter with her primary OBGYN:

He basically said, “Well, I am not comfortable telling you anything else so I am just going to punt to a specialist.” The words “I am going to punt to a specialist” really stood out very strongly in my head because I am like that’s not helpful, and you’re using a football analogy, and you’re telling me there is something wrong with my kid and you’re not helping us at all. There was no compassion there was no anything. It was just like hands off. I am not comfortable telling you anything other than we can’t see the heart or brain very well so I am going to push you off on someone else and pretty much that is all I am going to tell you.

Brynn captured a sentiment that was repeatedly described by participants who had a negative experience in the initial diagnosis. She explained her physician as follows:

There are the people who are medical professionals that come off as though they do this everyday. It’s normal to them and they expect you to know it. The words are way to big. They do it every day, but you have never heard of these things. Some of the things they think are simple are not simple to the brand new parent or even just a first time mother in general. There’s that category of doctor, they have a tendency to come off a little cold and distance.

Charlotte emphasized the above statement when she explained, “I felt like we were just a number. Like, he saw spina bifida every day it was no big deal.”

A final representative example of insensitivity is about the overall perception of the medical experience in that the physician judging the patient’s choice to have a baby at a given age or to not abort upon the diagnosis. Brynn commented, “‘He said you are going to be 36 when you deliver. So, what did you expect.’ Like I said, that was the worst experience I ever had. I was in such shock.” LaTasha described her initial spina bifida diagnosis as follows:

He’s like, “Well, why did you not get that blood test that tells you if something’s wrong?” and I said “Well, just because it didn’t really matter to us. You know, we had a healthy pregnancy first and then if something was wrong, I don’t know, we just didn’t do it. It wouldn’t have changed our course. And that’s when he brought up abortion. But he was like “I don’t know why you Oklahomans don’t believe in that.”

Specifically, the narratives that participants utilized to describe their physician-patient encounter indicated that physicians should consider the delicate balance of relaying a difficult diagnosis in a sensitive way. Additionally, participant’s responses suggested they felt that blunt word choice, poor metaphorical comparisons, and pointed questions about participant’s choices distanced them from the physician during initial diagnosis.

Relational Approach Varieties

Unlike the insensitive descriptions noted above, participants consistently described positive experiences with relational communication from physicians relaying an initial spina bifida diagnosis. More specifically, the initial encounter with the spina bifida diagnosis helped a physician build rapport and trust, develop emotional support and empathy, and eased the patient into the experience. Lailani stated that she and her physician “had a

really good bond. He was just kind of friendly, in a friend type of way.” Joy described her first visit with a specialist as follows:

When looking back, he [the physician] was kind when he presented it. His tone of voice, he was not harsh in any way. He really did not tell us what to do. And the nurses that were in the room, I remember they were compassionate in that they were not saying “I’m so sorry. I’m so sorry.” That is what the OB and the nurse did. They kept apologizing. And I did not know what was to be sorry about. If everyone is apologizing this must be really bad. So when we go to the specialist they were just sitting there doing their job. Getting me ready. They were commenting on how cute the baby was in the ultra sound.

Participants continuously discussed a physicians’ use of compassion, empathy, and support through their verbal and nonverbal messages in relaying information related to a spina bifida diagnosis. For instance, Shanna said, “I just remember him being a very calm, companionate man. Someone who was willing to just sit there and answer any questions that we had. He was pretty amazing.” Molly described her experience with the entire medical staff as “very compassionate.”

Participants also noted the importance of empathy. When asked how her physician could have approached the diagnosis differently, Charlotte said the following:

I do wish that the doctors and the practitioners would do a better job at imagining what it’s like to not know everything and not, you know, of being that family that has really no idea what this is going to look like. We’re not just another family going through this. We’re not just another number in the book.

Participants consistently described a variety of positive and negative experiences with their physicians regarding an initial spina bifida diagnosis. More specifically, their responses suggest that physicians can build rapport and trust, and develop emotional support by approaching the initial spina bifida diagnosis with empathy and allowing time for a patient to ask questions related to the diagnosis.

Discussion

The purpose of this study was to describe and explain the patient perception of the communication exchange by physicians upon learning that their unborn child had spina bifida. More specifically, this study adds to our conceptual description of communication in context of a spina bifida diagnosis to provide a more holistic understanding of physician-patient communication. The findings from this study provide insight and understanding into the types and ways that information is communicated to patients. Thus, participants provided an abundance of rich, descriptive information on communication strategies employed to understand a spina bifida diagnosis during pregnancy. As a result, the following conclusions can be derived from the current study: (1) patients’ perceptions of the initial spina bifida diagnosis explicitly described a variety of strategies employed by physicians to exchange information, and (2) this exchange of information was provided through various relational communication means. Understanding what strategies were employed to exchange information and provide a means of relational communication has implications for understanding best strategies for relaying difficult information during a medical encounter, which are explored below.

First, a number of factors influenced information exchange during the initial spina bifida diagnosis. One factor is taking a patient-centered approach, which has been identified as important in the medical encounter by previous research studies (Rao et al., 2007; VanDulmen & Bensing, 2002). VanDulmen and Bensing (2002) focused on physician-patient communication in regards to the amount of information provided in a medical encounter and suggested that physicians should take a patient-centered approach by allowing a patient to exert control over information exchange. Likewise, research stresses the importance of a physician repeating information along with providing opportunities for questions (Orioles et al., 2013; Oshea et al., 2007). As participants noted, there were a variety of positive and negative strategies used by physicians to provide information to patients in the current study. Strategies that were respected by participants included the honest acknowledgement about a physician’s lack of knowledge of spina bifida, providing patients opportunities to ask questions, providing immediate referrals to

specialists, providing literature, and connecting patients to social workers. The data suggests that patients desire to be active participants in the diagnosis process, which allows for patients to have some control during physician-patient communication. Previous studies found information as key in the physician-patient encounter, which allows patients to be active in the communication process (Orioles et al., 2013; Oshea et al., 2007). Allowing patients to freely ask questions without judgment along with providing connections with other professionals enables patients to begin advocacy for their child. Consistent with findings by Cegala (1997), DiMatteo et al. (1994), and Orioles et al. (2013), patients preferred a setting that allowed for questions, provided detailed disclosure, and allowed the flow of information in the medical encounter, specifically in the current study's context of information exchange between a physician and patient upon an initial spina bifida diagnosis.

In contrast, negative information exchange experiences derived from physicians who provided inaccurate information, those who did not own up to the fact that spina bifida was outside of general OBGYN practice, blunt messaging, and vague descriptions. The findings from this study indicate that participants perceived physician-patient communication ineffective when a physician exerted more control of the messages during the consultation, which directly relates to previous findings relating to lack of information leading to frustration, distrust, and overall satisfaction (Hoffman & Del Mar, 2014; Luff et al., 2016; Orioles et al., 2013). Therefore, information exchange strategies underscore the importance of allowing patients to feel that information was personally tailored, thus creating a sense of a physician as patient-centered (VanDulmen & Bensing, 2002).

Second, physicians used a variety of strategies to help effectively communicate the initial spina bifida diagnosis. Simultaneously, the relational communication findings are consistent with physician-patient communication exchange research focused on the need for rapport building and providing emotional support (Bensing, 1991; Orioles et al., 2013; Suchman & Matthews, 1988; VanDulmen & Bensing, 2002). The participants in this study provided data on the challenges of coping with effective and ineffective communication messages in a physician's relational communication. Although some participants experienced effective strategies to relay the spina bifida diagnosis, others experienced tensions when learning of the diagnosis through a perception of insensitivity. A patient-centered approach has been identified as useful for a physician to build trust, which should be approached with empathy (Bell, 2007). Consistent with findings by Kreps (1988), the findings unfortunately suggest that some patients experience insensitive communication approaches during the medical encounter. Perhaps some physicians are more concerned with establishing the seriousness of the diagnosis rather than caring for the emotional needs of the patient during the diagnosis delivery. In relation to findings by O'Hair (1989), relational communication provides physicians a means to build trust, intimacy, and control with patients. In the current study, participants received mixed messages that resulted in a variety of perceptions in relation to bonding and trusting their physician. Specifically, the descriptions provided by participants indicated how physicians were able to build or continue a relational bond along with maintaining the trust of a patient by employing relational communication strategies (i.e. empathy, compassion) during the initial diagnosis. Additionally, their responses suggested that physicians should value relational communication strategies to help ease a patient into a difficult diagnosis.

On a final note, Lechner et al. (2016) and Rabow and McPhee (1999) noted that communication training related to difficult conversations about a diagnosis is lacking for physicians. Understanding what parents perceive in the communication exchange during a spina bifida diagnosis has implications for understanding what kinds of communication training would be helpful for the future. While delivering a spina bifida diagnosis may be difficult for a physician, the way the diagnosis is approached from a communication perspective is important. The results of this study can inform the development of tools and educational trainings aimed to improve communication during a spina bifida diagnosis.

Tools and educational trainings should focus on cultivating informational-exchange experiences along with modeling and practicing empathetic communication related to the difficult conversation of diagnosing spina bifida during the medical encounter. Data from participants in this study provide some helpful tips on how this can be done, such as preparing notes or a detailed list of items to cover during the medical encounter as well as preparing thoughtful, direct words that explain the diagnosis to the patient. Furthermore, the data from this study points to the important role physicians have in providing opportunities for patients to ask questions, free of judgment, and repeating information when necessary. Additionally, another approach in educational training relates to active listening, which would teach physicians when to explore feelings and express sympathy.

Limitations and Conclusion

Although the current study provides a descriptive understanding of physician-patient communication in context to a spina bifida diagnosis, limitations exist. The first limitation is directed at participants. While the methodological choice to focus on female patients was necessary to provide an information-rich understanding of their experiences, the current study does not allow comparison across sex, and deliberately omits physicians' voices. Women were chosen for the current study since the diagnosis of spina bifida typically occurs during pregnancy. However, this may have influenced our results. It is possible that men perceive the physician-patient communication differently if present for the diagnosis. Additionally, physicians may have a different perspective of their communication during a diagnosis. A future study should include men and physicians to help give more description and understanding to the way a spina bifida diagnosis is disclosed to a patient. For instance, physicians can answer important questions related to their approach, why things are said, how they encourage and answer patient questions, and how interpersonal communication training is utilized during a spina bifida diagnosis.

A second limitation relates to information recall. Some participants were several years removed from the experience. While participants provided rich details to their experiences, at times detailed responses were unavailable by participants. This study relied on reflections of the past to understand the communication exchange of physicians and patients upon an initial spina bifida diagnosis. To circumvent these issues, a future study could incorporate ethnographic methods to explore the phenomenon as it unfolds.

This study extends the understanding of physician-patient communication by explaining and describing how information exchange and relational communication play out upon an initial spina bifida diagnosis. The current study sheds light on how patients perceive the communication of physicians during an initial spina bifida diagnosis, which allowed for a variety of strategies to relay information along with various relational communication tactics. It is very clear from this study that delivering a diagnosis about an unborn child, such as spina bifida, is very complex. Our hope is that scholars will continue to extend research focused on physician-patient communication to expand our knowledge of communication in the medical context.

References

- Aaronson, L. S., Mural, C. M., & Pfoutz, S. K. (1988). Seeking information: Where do pregnant women go? *Health Education Quarterly*, *15*(3), 335-345.
- Argyle, M. (1983). Doctor-patient skills. In D. Pendleton & J. Hasler (Eds.), *Doctor-patient communication* (p. 57-74). New York: Academic Press.
- Avtgis, T. A., & Polack, E. P. (2007). Predicting physician communication competence by patient perceived information exchange and health locus of control. *Human Communication*, *10*(2), 136-144.
- Beisecker, A. E. (1990). Patient power in doctor-patient communication: What do we know? *Health Communication*, *2*, 105-122.
- Beisecker, A. E., & Beisecker, T. D. (1990). Patient information-seeking behaviors when communicating with doctors. *Medical Care*, *28*, 19-28.
- Bell, E. F. (2007). Noninitiation or withdrawal of intensive care for high-risk newborns. *Pediatrics*, *119*(2), 401-403.
- Bensing, J. M. (1991). Doctor-patient communication and the quality of care. *Social Science and Medicine*, *32*, 1301-1310.
- Burgoon, J. K., Pfau, M., Parrott, R., Birk, T., Coker, R., & Burgoon, M. (1987). Relational communication, satisfaction, compliance-gaining strategies, and compliance in communication between physicians and patients. *Communication Monographs*, *54*(3), 307-324.
- Cegala, D. J. (1997). A study of doctors' and patients' communication during a primary care consultation: Implications for communication training. *Journal of Health Communication*, *2*(3), 169-194.
- Davis, D. L. (2010). Simple but not always easy: Improving doctor-patient communication. *Journal of Communication In Healthcare*, *3*(3/4), 240-245. doi:10.1179/175380710X12870623776397
- DiMatteo, M. R., Reiter, R. C., & Gambone, J. C. (1994). Enhancing medication adherence through communication and informed collaboration choice. *Health Communication*, *6*, 253-265.
- Dragonas, T., & Chistodoulou, G. N. (1998). Prenatal care. *Clinical Psychology Review*, *18*(2), 127-142.
- Elsenbruch, S., Benson, S., Rucke, M., & Dudenhausen, J. (2007). Social support during pregnancy: Effects on maternal depressive symptoms, smoking, and pregnancy outcome. *Human Reproduction*, *22*(3), 869-877.
- Frederikson, L. G. (1993). Development of an integrative model for medical consultation. *Health Communication*, *5*, 225-237.
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago, IL: Aldine Publishing Company.
- Guttman, N. (1993). Information exchange in medical encounters: Problems and problems. In B. D. Ruben & N. Guttman (Eds.), *Caregiver patient communications* (pp. 151-168). Dubuque, IA: Kendall Hunt.
- Hinds, C., & Moyer, A. (1997). Support as experienced by patients with cancer during radiotherapy treatments. *Journal of Advanced Nursing*, *26*, 371-379.
- Hoffman, T. C., & Del Mar, C. (2014). Less is more: Patients' expectations of the benefits and harms of treatments, screening, and tests. *Journal of American Medical Association Internal Medicine*, *175*(2), 274-286. doi:10.1001/jamainternmed.2014.6016
- Hulsman, R. L., Ros, W. G., Winnubst, J. M., & Bensing, J. M.. (1999). Teaching clinically experienced physicians communication skills. A review of evaluation studies. *Medical Education*, *33*(9), 655-668. doi:10.1046/j.1365-2923.1999.00519.x
- Kreps, G. L. (1988). Relational communication in health care. *Southern Speech Communication Journal*, *53*, 344-359.
- Lambert, S. D., & Loiselle, C. G. (2007). Health information seeking behavior. *Qualitative Health Research*, *17*(8), 1006-1019.
- Lechner, B. E., Shields, R., Tucker, R., & Bender, G. J. (2016). Seeking the best training model for difficult conversations in neonatology. *Journal of Perinatal Medicine*, *44*(4), 461-467. doi:10.1515/jpm-2015-0110
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage Publications, Inc.

- Luff, D., Martin, E. B., Mills, K., Mazzola, N. M., Bell, S. K., & Meyer, E. C. (2016). Clinicians' strategies for managing their emotions during difficult healthcare conversations. *Patient Education and Counseling, 99*(9), 1461-1466.
- Merriam, S. B. (1998). *Qualitative research and case study applications in education*. San Francisco, CA: Jossey-Bass Inc.
- O'Hair, D. (1989). Dimensions of relational communication and control during physician-patient interactions. *Health Communication, 1*(2), 97-115.
- Orioles, A., Miller, V. A., Kersun, L. S., Ingram, M., & Morrison, W. E. (2013). "To be a phenomenal doctor you have to be the whole package": Physicians' interpersonal behaviors during difficult conversations in pediatrics. *Journal of Palliative Medicine, 16*(8), 929-933. doi:10.1089/jpm.2013.0103
- Oshea, J., Smith, O., O'Marcaigh, A., McMahon, C., Geoghegan, R., & Cotter, M. (2007). Breaking bad news: Parents' experience of learning that their child has leukaemia. *Irish Medical Journal, 100*(9), 588-590.
- Patton, M. Q. (1980). *Qualitative evaluation methods*. Beverly Hills, CA: Sage Publications, Inc.
- Pendleton, D. (1983). Doctor-patient communication: A review. In D. Pendleton & J. Hasler (Eds.), *Doctor-patient communication* (p. 5-56). New York: Academic Press.
- Rabow, M., & McPhee, S. J. (1999). Beyond breaking bad news: How to help patients who suffer. *Western Journal of Medicine, 171*(4), 260-263.
- Rao, J. K., Anderson, L. A., Inui, T. S., & Frankel, R. M. (2007). Communication interventions make a difference in conversations between physicians and patients. *Medical Care, 45*(4), 340-349.
- Sjostrom, H., Langius-Eklof, A., & Hjertberg, R. (2004). Well-being and sense of coherence during pregnancy. *Acta Obstetrica Et Gynecologica Scandinavica, 83*(12), 1112-1118.
- Spina Bifida Association. (2015). Learn. Retrieved from <http://spinabifidaassociation.org/learn-about-sb/parents/>
- Street, R. L. (1991). Information-giving in medical consultations: The influence of patients' communicative styles and personal characteristics. *Social Science and Medicine, 32*, 541-548.
- Street, R. L., & Wiemann, J. M. (1988). Differences in how physicians and patients perceive physicians' relational communication. *Southern Speech Communication Journal, 53*, 420-440.
- Suchman, A. L., & Matthews, D. A. (1988). What makes the patient-doctor relationship therapeutic? Exploring the connexional dimension of medical care. *Annals of Internal Medicine, 108*, 125-130.
- Sunstein, B. S., & Chiseri-Strater, E. (2007). *Field working: Reading and writing research*. New York, NY: Bedford/St. Martin's.
- Thompson, T. L., & Parrott, R. (2002). Interpersonal communication and health care. In M. L. Knapp & J. A. Daly (Eds.) *Handbook of Interpersonal Communication* (p. 680-725). Thousand Oaks, CA: Sage.
- VanDulmen, A. M., & Bensing, J. M. (2002). Health promoting effects of the physician-patient encounter. *Psychology, Health & Medicine, 7*(3), 289-300. doi:10.1080/13548500220139421
- Warren, C. A. B., & Karner, T. X. (2010). *Discovering qualitative methods: Field research, interviews, and analysis*. New York, New York: Oxford University Press.
- Yin, R. K. (2009). *Case study research: Design and methods*. Thousand Oaks, CA: Sage Publications, Inc