OUT OF THE CHRYSALIS OF SILENCE INTO A WORLD OF

POSSIBLITIES: FAMILY EXPERIENCES OF HAVING A CHILD WHO

USES A SPEECH GENERATING DEVICE

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ABSTRACT

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OUT OF THE CHRYSALIS OF SILENCE, INTO A WORLD OF POSSIBLITIES:
FAMILY EXPERIENCES OF HAVING A CHILD WHO USES A
SPEECH GENERATING DEVICE

There are children in this world who are silenced by disability. The struggles of these children as they attempt to find a voice are difficult and often considered insurmountable. With advances in computer technology, devices are available to assist the child to have a voice. This voice is not found easily or acquired without difficulty. Even after finding and acquiring the necessary device, the child requires education and support to learn to use the device effectively. Challenges may be specific to the child's disability, the support systems involved with the child, or even the technology itself.

It is the adults in the child's life, and the child's family in particular, who provide needed support and assistance in helping him/her find an effective way of expressing his/her ideas. Families are an essential component in assisting their children to learn to use the device. My pilot study examined parents' likes and dislikes of their child's communication device. The preliminary data from that study illuminated several factors that increased the struggles of these children and their families as they work together to learn the device. These factors include financial, emotional, and developmental costs; as well as the lack of appropriately trained professionals; and excessive time lapses from evaluation to receipt of the device.

The purpose of this study was to give a voice to the experiences of families around a child's use of one type of augmentative and alternative (AAC), a speech generating device (SGD), by analyzing family's experiences of the child's use of a SGD

as seen through the lens of the child's primary caregiver. Interpretive phenomenologic methods for data collection and interpretation were used to elucidate the experience of families who have a child who is currently using or who has previously used a SGD as a method of communication. One cannot learn about the lived experience of the family without first listening to their story and allowing the family to share how their child's use of a SGD affected the life of their family.

Marsha L. Ellett, DNS, RN, Chair

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LIST OF ABBREVIATIONS

AAC	Augmentative and Alternative Communication
ALS	Amyotrophic Lateral Sclerosis
AT	Assistive Technology
ASHA	American Speech and Hearing Association
CD	Compact Disk
CP	Cerebral Palsy
HIPAA	Health Information Portability and Accountability Act
IEP	Individualized Education Plan
ISAAC	International Society for Augmentative and Alternative Communication
NIDCD	National Institute on Deafness and Other Communication Disorders
PECS	Picture Exchange Communication System
SGD	Speech Generating Device
ZPD	Zone of Proximal Development

CHAPTER ONE

Introduction

There are children in this world who are silenced by disability. The struggles of

these children as they attempt to find a voice are difficult and often considered

insurmountable. With advances in computer technology, devices are available to assist

the child to have a voice. This voice is not found easily or acquired without difficulty.

Even after finding and acquiring the necessary device, the child requires education and

support to learn to use the device effectively. Challenges may be specific to the child's

disability, the support systems involved with the child, or even the technology itself

(Oxley, 2003).

It is the adults in the child's life, the child's family in particular, who provide

needed support and assistance in helping him/her find an effective way of expressing

his/her ideas. Families are an essential component in assisting their children to obtain and

learn to use the device, a fact I discovered first hand when I adopted a child with

dysarthria from cerebral palsy (CP) who is now learning to use a communication device.

Our struggles with this device increased my interest in the struggles of other families with

children learning to use devices. This led me to conduct a pilot study examining parent's

likes and dislikes of their child's communication device. The preliminary data from that

study illuminated several factors that increased the struggles of these children and their

families as they work together to learn the device. These factors include financial,

emotional, and developmental costs; the lack of appropriately trained professionals; and

excessive time lapses from evaluation to receipt of the device. Augmentative and

assistive communication (AAC) has been instrumental in providing a method of

communication for those persons who have either been born without speech or who have acquired a language impairment due to illness or acquired disability. In particular, electronic devices such as speech generating devices (SGDs) allow those who are unable to speak to engage in the give and take of shared thoughts and information (National Dissemination Center for Children with Disabilities, 2004).

As a nurse who has worked with children with disabilities for the past 30 years and as the parent of a child who is learning to use a communication device, I have a profound interest in learning about the lived experience of other families and their children who are using a SGD. Certainly I bring along my experiences as both a professional and a mother to this research, but according to the work of Heidegger, all of us bring our own experiences along with us in whatever we do. The past is always in front of us (Heidegger, 1927/1962, p. 41). In other words our past provides boundaries for our future hopes and experiences. Our experiences provide us with a beginning place and lead us to the questions that we wish to have answered.

A dear, now deceased friend who suffered from amyotrophic lateral sclerosis (ALS) was delighted to share her experiences with me. She stated that she found the SGD difficult to use and discovered that no matter what type of voice was programmed into the device, telephone use was nearly impossible, and as an administrative assistant, this was a huge part of her job (M. E. Oberlander, August 22, 2006). She also stated she was frustrated about the inability to change voice inflection for emotions as the SGD only has a computerized, flat voice. My friend's declining health and the failure of the SGD to meet her needs led to her early retirement and abandoning the use of her SGD.

In discussing both the pilot and the current study with my peers, questions have arisen about how I will remain unbiased in the interpretation of the stories presented by the families who are being interviewed. I currently am part of a hermeneutic group consisting of two instructors, one of whom is very skilled in Heideggerian Hermeneutics, and graduate students learning to conduct research based on the works of Martin Heidegger. This group meets twice a month and examines de-identified transcripts with each member interpreting the transcripts for meaning. The interpretations are gifts to the researcher to help him/her broaden his/her perspectives. Each individual reads his/her interpretation aloud during class stimulating discussion. This allows the group to help identify important themes and patterns within individual transcripts and across transcripts rather than just one individual interpreting his/her data in isolation. This process allowed me to step back from what I thought I knew about the subject and see what other families in similar circumstances were experiencing. Further, it provided me with interpretations that I could not have reached on my own, because of my personal knowledge of the use of SGDs. I found myself relating to some experiences in the pilot, but I also discovered issues that I had not considered previously. Those new issues led me to this study exploring family experiences with their child's use of a communication device.

Purpose

The purpose of this study was to give voice to the experiences of families around a child's use of a SGD by analyzing family experiences of the child's use of the device as seen through the lens of the child's primary caregiver. Interpretive phenomenologic methods for data collection and interpretation were used to elucidate the experience of families who have a child who is currently using or who has previously used a SGD as a

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method of communication. Qualitative research, particularly interpretive phenomenology, is designed to find the hidden or concealed meanings of a phenomenon, such as using a SGD, through the expression of those who have experienced the phenomenon (Streubert & Carpenter, 1999). As Heidegger purports, one cannot learn about the lived experience of the family without first listening to their story and allowing the family to share how their child's use of a SGD has affected family life.

Aims:

1. Describe the experience of families who have a child who is currently using or has previously used a SGD as viewed through the lens of the child's primary caregiver.

2. Explore in greater detail the preliminary findings from the pilot study regarding financial, emotional, and developmental costs to the children and families, as well as the lack of appropriately trained professionals and excessive time lapses from evaluation to receipt of the device.

Definition of Terms

There are several terms that need defining when one is discussing any type of research involving families and their experiences. The following conceptual definitions were used for this study:

Family. Family was defined as "two or more persons who are related in any way—biologically, legally, or emotionally" (Institute for Family Centered Care, 2007). Family members were defined as family by persons within the family unit. According to Heidegger's idea of "throwness," people are thrown into the time, place, and family in which they exist (Heidegger, 1927/1962). People have no control over where they live,

when they live, or with whom they live; they just live and have only a limited ability to make changes in their life experiences.

Parent. The decision-making individual(s) in the family—may or may not act as head of household.

Sibling. Brothers or sisters who are biologically, legally or emotionally related—may be younger or older than the child. Siblings may or may not live directly within the family unit.

Primary caregiver. The person who provides the majority of care to and support for the child.

The lived experience. For the purposes of this study, the lived experience was defined as the way a person experiences and understands his/her world and what that experience means to him/her. The experience needs to be captured in language to be truly shared.

Interpretive Phenomenology. For the purposes of this study, interpretive phenomenology was the methodology used to interpret the phenomena of the lived experience by both allowing the phenomena to speak for itself and interpreting the stories of the persons who are experiencing the phenomena.

Augmentative and alternative communication device. Any device used to enable a person who is unable to speak or who has difficulty speaking to communicate more effectively. (see Table 1 for the types of devices available).

Speech generating device. A type of augmentative communication device that allows the child to formulate and express ideas either by typing in words or using a dynamic picture display which then provides a recorded or computer generated voice to speak aloud what has been inputed by the child.

Background and Significance

Freedom of speech is one of the rights guaranteed in the U.S. Constitution. Provision of devices that promote the use of speech for persons who would not otherwise be able to speak is supported by the Americans with Disabilities Act (1991). However, according to the National Institute on Deafness and Other Communication Disorders (NIDCD, 2006), between 6 and 8 million persons in this country have been diagnosed with language impairments and approximately 1 million of these people are suffering from aphasia. New cases of acquired aphasia number close to 80,000 per year. Approximately 1,428,568 children currently receive school services for speech or language disorders (American Speech-Language-Hearing Association, [ASHA], 2007). A 2007 study conducted by Binger and Light indicated that almost 12% of children receiving special education services in the state of Pennsylvania required some type of AAC services. This includes, but is not limited to, voice output communication or SGDs (see Table 1 for a list of the different types of AAC). For the purposes of this study, the device will be called a SGD as this term describes the device in a way that families can easily understand. Data for children younger than school age or who have communication disorders secondary to other physical or medical conditions are not available, so these statistics are truly a low estimation of the number of children who might require some type of AAC.

These disorders affect children differently than adults. Children who are born without speaking capabilities or those who acquire language impairments during early childhood may not fully develop an understanding of language. Many children who have significant neuromuscular impairments related to disorders such as CP or oral motor

dyspraxia are able to speak with maximal difficulty and minimal intelligibility, or they may not be able to speak at all (Ko, McConachie, & Jollett, 1998). These children are frequently referred for an AAC evaluation (Allaire, Gressard, Blackman & Hostler, 1991; Blackstone, 1989).

Lack of funding is a major obstacle for most families (Crisp, unpublished pilot study; McDonald, Harris, Price & Jolleff, 2007; McNaughton et al., 2008) and may preclude some families' abilities to obtain a device for their child. Currently there are no governmental supports in place for funding any type of AAC including SGDs. Each state makes decisions for funding AAC through public assistance on a case-by-case basis, but there are no mandated supports to provide AAC. By law, schools are supposed to provide AAC accommodations if included in the Individualized Education Plan (IEP), but the device supported by the IEP may not necessarily be the right device for the child and if it is, it may not be available when school is not in session. Family members must often take the role of staunch advocate to fight with the appropriate funding sources to find the money to pay for the device. Once again, this fight may be long and arduous leading to another developmental cavern for the child.

Limitations

As with any study with a specialized focus, the population of children using SGDs is small in comparison to the number of children who do not use SGDs, so recruitment of an adequate representation of families of children who use SGDs was somewhat challenging. By using multiple sites for recruitment, I was able to eliminate some of the difficulty in recruitment.

The participants from my pilot study were all middle class, educated women who were computer literate and able to find information and supports on the World Wide Web. The study may be representative of that population, but it may not be representative of persons who are lower in income, have less education, or fewer or no computer skills. Also, the costs of learning to use the device, whether they are financial, emotional, or developmental may be too prohibitive for some families with children who need the device. As stated above, most devices are quite expensive and families without insurance may not be able to obtain a device for their child.

Contributions to the Science of Nursing

The study broadened the science of nursing by providing insight, about how the use of an SGD affects all members of the family when a child uses a SGD. It also revealed concealed experiences of families who have a child who uses an SGD by providing an interpretation of family experiences with the child's use of a SGD as seen through the lens of the primary caregiver and identifying areas that are problematic. By sharing the lived experience, a greater awareness of the use of SGDs and the special challenges that are incurred in both the public and political has been revealed be revealed. Professionals who are exposed to the results of this study will gain a better understanding of the supports needed for positive outcomes, as well as an understanding of the detriment associated with costs associated with the device.

Nurses are in a unique position to help these families because nurses are often seen as the most trusted member of the child's healthcare team. Unfortunately, much of the recent AAC research has been conducted by persons in the speech-related and augmentative communication fields and very few studies have been conducted within the

realm of nursing. Those studies that have been within the realm of nursing have been

focused on the use of SGD in adults who have neuromuscular disease or who require

temporary communication support while intubated. Support in using SGDs has typically

been provided by augmentative communication specialists and educators as many nurses

have limited experience in the use of these types of devices. This study has identified

ways that the use of a SGD can be added to the nursing curriculum, thereby enabling the

nurse to take on a greater supporting role for families of children using the device,

leading to improved outcomes, such as continued use of the device when hospitalized and

a decreased rate of abandonment of the device.

CHAPTER TWO

Review of the Literature

The qualitative research process begins with a selective review of the literature

prior to data collection. This review is conducted to guide the development of the

research questions for the chosen topic. A brief description of qualitative research

methods will be provided followed by a discussion of Martin Heidegger's philosophy of

being (1927/1962), a discussion of his philosophy regarding the use of technology

(1954/1977b), and a brief discourse on Heidegger's thoughts about language will serve to

describe the philosophical underpinnings for the research question, "What is the

experience of having a child who uses a speech generating device?" A description of the

current AAC research will be presented, followed by a review of literature regarding the

role of the family in the use of AAC, social theory and how it affects the perceptions of

the child who uses a device, and the development of language in young children. Finally,

the chapter will conclude with a summarization of the literature pertaining to child and

family experiences with AAC.

Qualitative Research Methods

Qualitative research seeks to explore the human experience as described by the

persons who have lived the story (Farley & McLafferty, 2003; Seidman, 1991). Denzin

and Lincoln (2005) say the following about qualitative research:

> Qualitative research involves the studied use and collection of a variety
> empirical materials—case study; personal experience; introspection;
> life story; interview; artifacts; cultural texts and productions;
> observational, historical, interactional, and visual texts—
> that describes [sic] routine and problematic moments and meanings in
> individuals' lives (pp. 3-4).

Qualitative research is research that provides a meaning that can only be derived from conversations of persons who have traveled the path being investigated (Streubert & Carpenter, 1999). This type of research is not quantifiable, but it is no less valuable as it provides insight into lives and meanings that could not be captured using conventional testing measures. It is more holistic and flexible than quantitative research methods, allowing for a deeper understanding of the subject matter and its effect on the lives of the persons in the population being studied (Farley & McLafferty, 2003).

Phenomenology. This method of qualitative research arises from the realm of philosophy and focuses on understanding the essence of a phenomenon. According to Donalek (2004), phenomenological nursing research provides for the exploration and description of the deepest meanings of the human health-illness experience.

Phenomenology provides a way for the investigator to explore the "lived experience" from the perception of those persons who either have or are experiencing a specific phenomenon. These phenomena cannot be experienced by any other persons or groups other than the ones being studied. This study of a specific group allows for a glimpse into the lives of persons actually living the experience. Phenomenology requires that the researcher dwell with and become a part of the data. It is not enough to simply identify the main themes and ideas presented in the data; a thorough analysis of how the themes and ideas interact in the "lived experience" is also required. Phenomenology searches to find statements leading to essences of all the phenomena contained within the data in an effort to gain a more personal perspective of the actual lived experience (Donalek, 2004; Streubert & Carpenter, 1999).

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Heideggerian hermeneutics is underpinned by the works of Martin Heidegger's philosophical teachings. Hermeneutics is not considered atheorectical; rather no specific theory underpins the hermeneutic process. This allows for researchers to come into the experience with their own set of beliefs, perceptions, and experiences that influence the research and function as part of the overall research process including the interpretation of the study findings (Farley & McLafferty, 2003). Phenomenology focuses on wanting to know about how different populations function within the world that we know. Researchers who utilize interpretive phenomenology should look for themes, paradigms, and exemplars that suggest similarity of thought and/or actions that may imply consistency in viewing a given phenomena by a group of related individuals (Benner, 1994; Conroy, 2003).

The Philosophy of Heidegger

Martin Heidegger was a 20th century German philosopher who tried to shift the focus of phenomenology to an ontological standpoint (how individual persons interpret the world) instead of an epistemological viewpoint (why we know what we know) (Leonard, 1994). An understanding of what it means to be a person in a given experience provides knowledge about how that person views the world and leads us to Heidegger's philosophy of Being-in-the-world. *Dasein* is the term used by Heidegger to describe the aspect of being human that seeks to find the meaning of Being in the world as a being of the world (Heidegger 1927/1962). In other words, Dasein seeks to describe the world view from the picture postcard in which we live. Each experience is a snapshot of a moment in time, and only the person living the experience understands the meaning of the experience unless that experience is shared with others through phenomenology.

Ontology, or the study of Being, was proposed by Heidegger as the only way to gain an understanding of the conditions that allow other conditions to exist. His use of the capital "B" to delineate the meaning of Being, an understanding of what it means to be living an experience, from being, is very complex. The concept of being is described as everything else that exists in the world: people, places, technology, things, and all of the complexities associated with being (Lemay & Pitts, 1994). These ideas, first proposed in the paper *Being in Time* (Heidegger, 1927/1962), underscore Heidegger's philosophy on how people exist within the world. Being in the world is essential to Dasein and cannot be separated from the concept.

The Meaning of Being. "Being in" is *existential* in nature. It is the part of Dasein that refers to being and how one understands the engagement of experiences that provide life-meaning definitions for those who have experienced a given situation (Heidegger, 1927/1962). It is the interaction between Being and being that provides meaning. Heidegger's idea of *thrownness* provides us with an explanation of how we arrive at where we are in a given situation. Each person is thrown into a world in which we are already involved, but a world in which we have no control over family, culture, time, or circumstances. However, it is a world in which we are already experienced and able to exist. Our everyday experiences, or our Being in the world, are so familiar, that we often lose track of them or take them for granted. It is in the description of what has happened to shape our experiences that leads us to the hidden meanings of phenomena.

All persons live in the same shared world; thus, all the similarities in our backgrounds allow us both shared and individual interpretations of the world which leads to Heidegger's concept of "the clearing" (Heidegger, 1927/1962). According to Dreyfuss

(2008), our shared background provides us with our understanding of the things in our environment, what is important to us as human beings, and how we make sense of what we do in our lives. We use these understandings to direct our actions toward the people and things that surround us. This is the place where specific experiences are revealed and shared. That which is hidden becomes visible and is seen for what it really is. This understanding of Heidegger's concept of Being reveals the meaning of Being in a real context, much like the purpose of this study. By exploring how children who are learning to communicate via a SGD and their families experience the journey, the meaning of this journey is revealed within its own context with interpretation.

The Meaning of Technology. Heidegger did not begin to explore technology until much later in his career. In his early works, Heidegger contended that technology was a dangerous thing and that man would use it for his own purposes dominating everything and exploiting others along the way just because he could (Dreyfuss & Spinosa, 1997). However, as the reign of the Nazis diminished and technology became more accessible to the people, Heidegger revised his thinking. Heidegger considered thinking as an activity that cannot be performed independently or abstractly from reality and that thinking provides man's "most essential method of being man" (Heidegger, 1954/1977b). In his work, *The Question Concerning Technology,* Heidegger discusses what he calls "the darkening of the world" and describes the issue of the dehumanization of modern society in post-World War II Germany. His view of technology changed to "technology's essence is by no means anything technical (p. 4)." Technology is defined as a way of revealing. "Technology comes to presence in the realm where revealing and unconcealment take place, where *alētheia,* truth happens (p. 13)." There is no separation

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between man and technology, only a revealing. Heidegger also proposes that technology precedes and influences science rather than science preceding and influencing technology.

The word technology is derived from the Greek word technē, first used by Aristotle to describe the process of producing a specific product.

> The SKILL, ART, or craft and general know-how, the possession of which enables a person to produce a product. The term is used not only to describe, for example, the kind of knowledge a shoemaker needs to produce shoes, but also to describe the art of a physician which produces health, or the skill of the harpist which produces music (Aristotle, 1962, p. 315).

Technē is basically making things out of something else: a sculptor may be able to see a beautiful statue in a huge piece of granite, a child may be able to see the snake in a ball of Playdoh, a Native American may see a totem pole in the trunk of a tree. It is a sense of creating something from things. According to Heidegger (1977a, p. XXV), technē was a "skilled and thorough knowing that disclosed…a mode of bringing forth into presencing, a mode of revealing." It is a way to show how to use what we have to make something else, the know how to make something from nothing. It helps us to see the essence in the technology that we use every day.

The essence of technology proposed by Heidegger does not refer to technology as most people consider it but rather as a specific way of seeing the world, a way of looking at how everything in the world is revealed. Everything that is in the world is available for beings to use and technology transforms beings into *bestand* (resources that are standing in wait for consumption) which allows things to be made ready for use within the world. Heidegger maintained that the essence of technology is part and parcel of the revealing of being which allows for the revealing or "laying bare" of the phenomena (Walton, 2000).

The need for resources to be ready for consumption has created a society in which all things are expected to be ready-to-hand and available to use when and where they are wanted (Harman, 2007; Wrathall, 2005). Things that are ready to hand are those things that are taken for granted as always being there ready for use in the world around us (Ironside, 2009). Our society wants to be able to get the most they can out of everything, a kind of the "biggest bang for the buck" type of mentality. When this does not happen, breakdown occurs. It is often the breakdown of technology that draws our attention to it. It is the breakdown of the systems surrounding the child's use of a SGD that has drawn my attention to the need for further investigation into the lived experience of the child and family who are living with an SGD, and it is through interpretive scholarship, that I can explore the meanings of the use of a SGD to the family.

"Interpretive scholarship increases the understanding of the meaning of living a life-sustained-by-medical-technology that joins human experience and technology in ways that are only beginning to be explored (Sloan, 2002, pp. 120-121)." There is no real separation between the person requiring the technology and the technology. They become one and the same, and we are only able to discover the true meaning of living with technology by exploring the lived experience of those persons who are living with technology.

The Importance of Language

According to Heidegger (1971a, p. 124), language speaks to us. It is something that is encountered in all aspects of life and is a huge part of understanding the world in which one lives. Speech is natural to us. Speech allows man to live as a being. "Speaking is of itself a listening. Speaking is listening to the language which we speak. This is a

listening not while but before we are speaking (Heidegger, 1971a, p. 123)." We reflect on

language to learn about language itself. This reflection on language leads to the further

study of language development throughout the lifespan.

> Heidegger is not so much interested in the logical structure of language as
> in the role the different languages play in establishing different styles of
> being in the world. For Heidegger, the key feature for understanding
> language is to focus on our responsiveness to it, that is, the way it
> shapes and guides our understanding of ourselves and the world around
> us 'before we are speaking' (Wrathall, 2005, p. 89).

This reflection on language becomes very important for the child who is using a SGD

because the response of others to the device is so integral in the child's understanding of

him/herself and the world. The SGD is part of the being of the child's Being, and one

cannot be separated from the other. Engaging in conversation allows the language to

come to us and reveal the message that is being conveyed. The same holds true for users

of the SGD. If one truly listens and focuses on what the child is expressing, new insight

and understanding about the child and his/her world are revealed.

Early insights and understanding are usually revealed to the family members who

are closest to the child. In many instances the child and family have already identified a

way to communicate, but the use of the SGD makes that communication easier. The role

of the family as a communication partner is vital as the child learns to use the device.

The Role of the Family

There is currently a high abandonment rate of SGDs among children who are

unable to speak (Guidera & Olsson, undated; Pendergrass & Vestal, 2002). This is due in

part to failure of the family to "buy in" to the new technology. Family members are

considered to be one of the child's most important communication partners (Anderson &

Battle, 1993; Hetzroni, 2002; Parette & Angelo, 1996; Pendergrass & Vestal, 2002;

Renner, 2003) They are often not as excited about the prospect of the life changes that occur with the introduction of technology into the home as the healthcare team might like (Glennon & DeCoste, 1997; Kintsch & DePaula, 2002; Wang & Barnard, 2004). Supporting and assisting the child to learn the new technology frequently requires considerable work on the part of the parents and sometimes the siblings as the child will need to practice his/her new language skills much the same as any other child who is learning to speak.

Previous studies conducted with adults using AAC indicate that the most successful outcomes are achieved by those users who experienced support and commitment of family members (Silverman, 1989; Van Dyck, Allaire, & Gressard, 1990). There have also been a number of studies indicating the importance of family involvement in the successful use of AAC by children who are unable to speak (Angelo, 2000; Angelo, Jones, & Kokoska, 1995; Cress 2004; Parette, Vanbiervliet, & Hourcade, 2000).

There are no studies that actually investigate the specific roles of parents and/or siblings in achieving success with AAC, nor have any studies investigated the impact of AAC on all members of the family of the child who is unable to speak and is learning to use a SGD. None of the previous studies employed qualitative research strategies to determine the effects of using speech generating technology on the family. Qualitative research, particularly interpretive phenomenology is designed to find the hidden or concealed meanings of phenomenology through the expression of those who have experienced the phenomena (Streubert & Carpenter, 1999). One cannot learn about the lived experience of the child and family members without first listening to their stories

and allowing each member of the family to share how the child's journey to communication affects his/her life.

Social Theory and Its Effect on Perception

Social theory is also important when one is considering issues surrounding small populations. Symbolic interactionism plays a role in the misunderstanding of use of SGDs in children who are not society's picture of "the perfect child." Goffman's work (1962/1986) with analysis of stigma is very similar. According to his work, people are either considered "normal" or deviant. Goffman defines stigma as an "attribute that is deeply discrediting, reducing the person that possesses a particular quality from a whole and usual person to a tainted and discredited one" (p. 3). A child in a wheelchair using a computer to speak has a different social identity than a child who is typically developing. This leads to social apathy or social stigma that is often difficult to overcome, especially in a world where there are few persons able to provide education regarding the use of SGDs.

The social stigma may cause the child and family to consider the use of a SGD as a negative because it brings more attention to the child. "It's just one more thing to have to carry around with us." This stigmatization may lead to ambivalence or may cause the child to strive harder to prove that he/she can function within society. These children learn ways to cope and handle themselves leading to greater acceptance among those people whom they encounter in their day-to-day existence (Carnevale, 2007).

Augmentative and Assistive Communication Research

Since the mid 1980s there has been a push for the use of augmentative and assistive communication (AAC) to improve communication in children who are unable to

speak or who have severe language impairments. AAC is considered "an area of clinical practice that attempts to compensate (either temporarily or permanently) for the impairment and disability patterns of individuals with severe expressive communication disorders" (ASHA, 1989, p. 107). Most of the research conducted is inclusive of all types of AAC and is not specific to the use of SGD.

Table 1 provides an explanation of the different types of AAC. The device may be very simplistic (such as a communication board using simple pictures or a picture exchange system (PECS) or as complex as an eye gaze speech generating computer. The device is individualized to the user depending on his/her communication and technology needs. Perhaps the most recognizable use of a SGD in the public eye is physicist, Stephen Hawking, author of the Big Bang Theory. He has suffered from amyotrophic lateral sclerosis (ALS) for several years and has made the use of a SGD and other types of AAC more accepted in the academic realm.

The use of AAC methods has increased dramatically in the past 25 years. AAC is being used for adults who require temporary ventilation secondary to illness, persons with progressive neuromuscular diseases, persons with brain injury, children and adults with multiple disabilities, and persons who are aphasic (Calculator, 1999; Carter & Maxwell, 1998; Doyle & Phillips, 2001; Happ, 2001; Happ, Roesch, & Garrett, 2004; Happ, Roesch, & Kagan, 2005; Happ, Tuite, Dobbin, DiVirgilio-Thomas, & Kitutu, 2004; Johnston, Reichle, & Evans, 2004; Jones, 2004; Light, Collier, & Parnes,1985). With this increase in the use of AAC comes the knowledge that stakeholder accountability is required for the successful implementation and continued use of the

chosen method of AAC (Johnson, Inglebret, Jones, & Ray, 2006). However, there continues to be a huge rate of abandonment by AAC users and their family members.

AAC users and their family members are considered essential members of the augmentative communication team and are involved in all aspects of AAC decision making from the choice of the method, its implementation, and continued use (Glennon & Decoste, 1997). The training of all possible communication partners has been found to be essential in teaching children with severe neurocognitive delays to communicate effectively (Buzolich & Lunger, 1995; Calculator, 1999). Parents have been identified as the most important persons involved in communication learning in young children (Parette & Huer, 2002; Renner, 2003). The most successful child users of communication devices are those children whose decisions and training are family centered (Bailey, Parette, Stoner, Angell, & Carroll, 2006). It is readily apparent that the parent and family are important members of the AAC team. Without the parent's participation, the child needing AAC will not have all of the tools needed to learn to use the recommended speech output device.

Parette (2000, 2002) has been instrumental in conducting a variety of studies as well as assisting Vanbiervliet in the development and implementation of the *Families, Cultures, and Augmentative and Alternative Communication* multimedia program (Parette & Vanbiervliet, 2000; Vanbiervliet & Parette, 2002). This intervention program was designed based on the premise that culturally-related, family-focused informational programs are needed to assist in the successful use of AAC among young users. This multimedia program has been very beneficial in improving compliance with ordered AAC devices in both the English- and Spanish-speaking populations.

Other researchers have focused on perceptions surrounding AAC users and included studies conducted with AAC users, family members, and peers. Clarke, McConachie, Price, and Wood (2001) studied perceptions of children and young adults who were actual AAC users in Great Britain. They were able to identify usefulness and perceived benefits to use as two of the predominant reasons to continue using AAC devices. Other studies, such as the one conducted by Angelo and co-researchers (1995) and the one conducted by Bailey and co-researchers (2006), focused more on family perceptions of the use of AAC devices. Some of the needs identified by families are the need for family-centered care in which the needs of all members of the family, not just the child with a disability are met. Fathers identified a need for knowledge to be the most important consideration. Both parents considered information and planning about future communication needs to be important. Mothers were interested in how to integrate the use of AAC into the community and at home. They also wanted more information about the supports available in the community.

Peer interaction has also been the focus of study (Beck & Dennis, 1996; Clarke & Kirton, 2003). Children requiring the use of AAC were perceived more negatively by their peers than children who did not have any communication difficulties. Girls were more accepting than boys of a peer's differences. Acceptance by peers is seen as a powerful motivator for children to learn to communicate more effectively. The perceived benefits seem to be less of a concern to young children than acceptance by peers.

McCarthy and Light (2005) conducted a review of 13 studies about attitudes of others toward persons who used AAC devices as a primary method of communication. They discovered that a number of characteristics influenced attitudes including

developmental characteristics of the individual, gender, and the type of output provided by the device. Once again the themes of usefulness and perceived benefits were listed as being important to the study subjects.

Another area of research focused on the dyadic relationship between non-speaking users of AAC devices and their communication partners (Higginbotham, 1989). The results of this study provided support that certain types of communication aids were beneficial in improving communication between dyads of one speaking and one non-speaking participant. It also identified the importance of the dyadic relationship between the person using the device and his/her communication partner. Unfortunately in this study, both persons in the dyad were able to speak and had a relationship prior to testing. The same research has not been conducted using dyads of one speaking person and one non-speaking person who have no prior relationship.

Other researchers investigated outcomes following recommendations for augmentative communication (Ko et al., 1998; Pendergrass & Vestal, 2002) and reasons for success or failure of the implementation of the device. Some of the factors noted to have influence on the adoption of the use of the device included the time the device was received from the time it was ordered as those persons who received their device in a timely manner were more likely to use the device; adequacy of local training to learn to use the device; and children who were age 6 years or older. In their article, Ko and co-researchers recommend improved information, interagency planning, and co-ordination as methods to improve outcomes.

The research strongly identifies the need for parental involvement and a need for increased knowledge as two factors needed to promote successful usage of AAC devices

in children. Unfortunately, much of the early work in the area of AAC was not based on research and is primarily anecdotal in nature. Other studies are limited by the small sample size as many studies are single subject case studies. Many of the early research articles fail to describe the research design.

One of the greatest limitations to current AAC research is that it has been conducted between speaking partners and/or typically developing children (Drager et al., 2004; Drager, Light, Speltz, Fallon, & Jeffries, 2003; Light & Drager, 2002). This does not lead to a true picture of the effect of AAC on the life of a child or young person with developmental disabilities who is unable to speak. Further research needs to be conducted with persons actually using the devices to insure better trustworthiness of the findings.

A second limitation is that little research has been conducted to evaluate the efficacy of using a SGD. Most of the existing research was conducted by Happ in her work with adults who communicate via an AAC device while intubated and on a ventilator while recovering from illness or surgery (Happ, 2001; Happ, Roesch & Garrett 2004; Happ, Roesch & Kagan, 2005; Happ, Dobkin, Diviglio-Thomas, & Kitutu., 2004). The temporary loss of the ability to communicate is very stressful not only for the people who require ventilation but also for the professional caregiver and the family members of the person requiring mechanical ventilation. As with children who are unable to speak, the family member often takes the role of interpreter for the person who is unable to speak (Happ, 2001). Professional caregivers and persons requiring mechanical ventilation often devise a plan to utilize gestures, eye gaze, and eye blinks for simple communication. Communication regarding pain is frequently misinterpreted, and persons

who are unable to communicate may not receive the same degree of pain management as persons who are effectively able to communicate the level of pain being experienced.

The inability to communicate while requiring mechanical ventilation has been described as both terrifying and isolating by persons who have experienced the need for temporary mechanical ventilation during recovery from illness or injury (Happ, Roesch, & Garrett, 2004). The use of AAC methods, including SGD devices, can greatly improve communication in this population while decreasing fear and isolation; however, this technology is not appropriate for all persons requiring mechanical ventilation. Persons in the intensive care unit recovering from some type of illness or injury having frequent changes in medical status are unable to be maintained in the best position to read and utilize the device, may not be familiar with the complexity of the device, and may have staff taking care of them who are unfamiliar with the device. Also, even though many of the devices have pre-programmed messages selected by the patient prior to surgery, not all needed communication phrases may have been included leading to more frustration and feelings of isolation.

The current studies indicate a need for some type of communication assistance for clients requiring mechanical ventilation while recovering from illness or injury. However, the studies also indicate that further investigation is needed to insure that devices used with this population of clients are more user-friendly and have more messages programmed into them to insure that clients are able to communicate effectively with family members and professionals caring for them.

Another group of adult patients who frequently use a SGD are those persons with neurodebilitating diseases such as ALS (Fried-Oken et al., 2006; Zeitlin, Abrams, &

Shah, 1995). In their 2001 study, Doyle and Phillips identified the trends in AAC use by persons with ALS. A number of AAC options exist for persons with ALS depending on the degree that their speech is affected and their ability to perform everyday activities. One of the trends is for the person to use multimodal methods of communication: a low technology device such as writing board or note for written communication and then some type of SGD for speaking on the telephone. Oftentimes the type of AAC device selected is based on communications needed with the partners and the environment in which the person lives on a daily basis. Portability of the low technology options often make them preferable over a higher technology device such as a SGD.

Attitudes about communication in storytelling by persons with ALS were explored by Richter, Ball, Beukelman, Lasker, and Ullman (2003). The researchers investigated attitudes regarding three types of communication modes utilized to tell stories by persons with ALS. The modes explored were unintelligible natural speech, communication notebook, and a SGD using synthesized speech. Listener groups showed a strong preference for the storytelling completed using synthesized speech, even though study participants recommended that future devices be designed that allow for greater message storage and retrieval. Many of the current SGDs do not allow for more than just short messages or phrases.

It is readily apparent that more and better types of AAC devices, including those supporting speech generation, are being utilized by a wide variety of clients in a number of settings. Unfortunately, the technology does not always meet all of the demands of the person using it; however, technology is constantly being refined and redesigned to make it more user friendly for all kinds of people in all types of settings. In the words of

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Catherine Wolf (2007), a SGD user, "There are new technologies in development—some even use brain waves to allow you to communicate. So keep writing. If you have the words, and we all do, someone can help you bring them to fruition (p. 41)."

Family Adaptation to Technology

All members of the family, including some extended family members, are affected when there is the requirement for any type of technology to be used in the home. The perception of those family members about the positive or negative effect of the technology is important to the adaptation of the user and the family to the needed technology (Angelo, 2000). Adding technology to the stressors already being experienced by the family of a child with chronic illness or disability can be overwhelming (Baum, 2004; Hovey, 2005; Jones, Angelo, & Kokoska, 1998; Krafft & Krafft, 1998; Montagnino & Mauricio, 2004). Negative stressors associated with the implementation of the new technology could have an effect on the way the child and family perceive the needed technology.

Much of the literature pertaining to assistive devices in the pediatric population involves technology dependency (Ingadottir & Jonsdottir, 2006; Kirk, 1998; O'Brien, 2001; Rehm & Bradley, 2005; Wang & Barnard, 2004). Advances in technology enable more premature babies and children with chronic illness or injury to survive and leave the hospital. As more and more of these children who are medically fragile and are technology dependent successfully make the transition from hospital to home care, the number of family caregivers required to learn to utilize the technology dramatically increases. Children who are technology dependent require the use of some type of technology to help them compensate for a lost vital body function (Kirk, 1998) whether it

be speech, vision, hearing, or breathing. Parents of children who are technology dependent may find themselves isolated from their friends, overburdened with the responsibilities and care demands placed upon them, as well as attempting to keep up with the financial burden of insuring that the child has all the equipment needed to have a productive life (Carnevale, 2007; Kirk, 1998; Wang & Barnard, 2004).

Parenting a child with chronic illness, injury, or disability can be difficult and sometimes confusing. The parent not only has to conduct the regular business of parenting but must also become a caregiver responsible for ensuring that all needed assistive technology is functioning correctly (Wang & Barnard, 2004). Family relationships such as those with siblings may also be affected because of the additional time needed to meet the needs of the child requiring the technology. Siblings may demonstrate behavioral difficulties or negative sibling relations related to jealousy resulting from a perception that the child with the illness, injury, or disability receives more time and affection than the able-bodied sibling.

These as well as a number of other factors may be involved in the parent's reluctance to learn a new technology with their child. Some of the reasons cited by parents for not wanting to participate in the child's learning of the needed skills include a lack of motivation due to fears about the parent's inability to use the device, the amount of time needed to program and maintain the device (Calculator, 1999), inadequate training to use the device, and a lack of understanding about the benefits of improved communication to the child and family (Bailey et al., 2006; Jinks & Sinteff, 1994; Kintsch & DePaula, 2002). Other barriers include a profound lack of models to support parents in assisting their child learn AAC (Parette & Marr, 1997; Sigafoos et al., 2004),

the cost of the device (Browder, Anderson, & Meek, 1986), and the lack of supportive

documentation for the insurance companies to pay for the device, as well as the cost to

effectively train the child and family to use the device. Finally, one of the largest barriers

to the use of a communication device is the child and family's inability to integrate the

technology into everyday life (Kintsch & DePaula, 2002).

While the literature base about the use of assistive technology continues to grow

as more and more people begin to utilize the different types of devices, there remains a

deficit in the amount of research conducted with children who utilize assistive technology

and their families. One of the gaps that has been identified in the AAC literature is the

need for further research about how children and families are affected by the inclusion of

AAC in their lives (Angelo, 2000; Glennon & DeCoste, 1997). It is likewise important to

investigate the user and family influence on the success or failure of using one of the

AAC methods (Silverman, 1989; VanDyck, Allair, & Gressard, 1990).

Language Development in Young Children

 "Language is a tool that children use to plan their actions, remember information,

solve problems, and organize their behavior" (Siegler & Alibali, 2005, p. 115).

Development of cognition and language continue to be important in the psychological

and social development of all persons (Vygotsky, 1989); therefore, both an understanding

of language development in all children and an understanding of language development

in children who learn to communicate using some type of AAC device are needed.

Language development during the first 18 months of life is very gradual (Davies,

2004). It is almost as if language development occurs without any effort and just happens

as the brain matures (Frederici, 2006). There are recognizable milestones of language

development that begin soon after birth and continue until the child reaches the age of 4 years (see Table 2), with most of the development occurring during the toddler period. At about 18 months of age, the child becomes aware of the power of language and begins to assert him/herself in an effort to be understood (Davies, 2004). The increased level of language development at this particular age is believed to be due in part to growth in the cortical parts of the brain that function in language. Toddlers gain an understanding of the meaning of about 50 words between the ages of 13 and 18 months, but they lack the ability to speak those words until they are 18 to 22 months old (Davies).

Children have an understanding of the words being spoken before the child actually learns to speak a word (Davies, 2004). This is important in the consideration of the cognitive abilities of a child who is unable to speak, but who has good receptive language skills. To learn a language, the child must learn a combination of sounds, phonology, semantics, and finally grammar (Roberts, Price, & Malkin, 2007; Slater & Lewis, 2007). The initial form of communication is the differing cries of infancy. The different cries for hunger, discomfort, need for attention, and anger are soon identified by caregivers leading to the infant's needs being met. Many of these early communication attempts are felt to be innate (Paul, Chawarska, Fowler, Cicchetti, & Volkmar, 2007; Slater & Lewis). As the child matures, he/she begins to learn language from the people in his/her environment. The language of the caregivers becomes the language of the child. One possible explanation for this involves Vygotsky's theory of the Zone of Proximal Development (ZPD) which simply stated is the difference between the child's independent abilities and the abilities the child is capable of performing with the assistance of an adult, educator, or caregiver. This adult assistance is known as

scaffolding (Holaday, LaMontagne, & Marciel, 1994; Rutland & Campbell, 1996; Sanders & Welk, 2005; Siegler & Alibali, 2005; von Tetzchner & Grove, 2003; Vygotsky, 1978). The concept of scaffolding means that the people in the child's environment take an active part, not only in presenting information that needs to be learned, but also by providing support for the child as the child fights to find a voice.

Children learn from persons in their environment, so if a child is reared in a bilingual environment, he/she will likely be bilingual, a child born to parents who are deaf will learn to use sign language for communication, and children who never or rarely hear the spoken word such as those children reared in orphanages in underdeveloped countries will not learn to speak at all. They will use innate cries and some gestures, but they will be significantly delayed in other areas of language development (Windsor, Glaze, & Koga, 2007). A child who requires an AAC device has few models to learn from in the environment as most people surrounding the child are able to communicate verbally (Oxley, 2003).

A study currently in progress in the Plano Independent School District in Texas is examining language and social development in six children who SGDs. These six children are piloting a classroom environment for SGD users. The study began approximately 1 year ago and will continue for 3 years (Rummel-Hudson, 2008). This type of classroom will provide the children with the opportunity to receive instruction in the use and language of the device as well as providing the children with an environment that will allow them to grow and flourish among peers with similar issues. Opportunities are also provided for the children to interact in regular classrooms with typically

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developing peers. Further information on this program can be found at

http://k12.pisd.edu/currinst/sped/AT/AAC_users.htm.

Vygotsky (1993) supports the *people first* concept. Whatever disability the child has is a normal state for that child and is not a disease process. He suggests that social segregation and the interventions provided for the SGD are important for the child's mental development and have a much greater impact on the child's outcome than the disability itself.

Children typically begin to utter their first word at approximately 1 year of age. Prior to uttering that all-important first word, children use gestures, facial movements, expressions, and vocalizations to communicate (Roberts et al., 2007; Slater & Lewis, 2007). Children with significant physical and mental handicaps may remain in this stage for a prolonged period of up to years or for a lifetime if the handicap is significant enough (Roberts et al.) For some of these children receptive language continues to develop even though expressive capabilities lag behind. This split between receptive and expressive language can in part be explained by the Zone of Proximal Development as the child's actual understanding of language (or independent performance of language tasks) exceeds his/her potential ability to express it (Siegler & Alibali, 2005).

Language development in children who require AAC devices is not clearly understood. von Tetzchner and Grove (2003) stated that "a critical distinction between the acquisition of spoken or sign language and that of alternative communication is that they originate in different ways" (p. 2). Whereas typically developing children develop language by communicating with those people around them, children who use an

augmentative device acquire language through a process of intervention designed by parents, teachers, and AAC professionals.

One of the gaps recently identified by von Tetzchner and Grove (2003) is the fact that there are many studies that examine the language development in young children who are learning to speak as well as multiple studies that examine how deaf children develop language using sign; however, there are no studies that examine the development of language in children who use AAC. This information is needed to provide adequate supports to children who are learning to use AAC as their way of communicating with others.

A critical question posed by Renner (2003) is how augmentative communication supports adequately reflect the physical and social world. The use of a SGD can open up new worlds of communication for the child, but most devices do not have the vocabulary capacity of children who have learned language in the typical way. The devices also may not have adequate choices for children of different backgrounds and cultures (McCord & Soto, 2004). Other related issues include difficulties in measuring literacy skills, a lack of provision for proper grammar, and difficulties related to sentence structure. Many devices contain nouns, some verbs, and adjectives, but adverbs, prepositions, and conjunctions are not available (Renner).

While there is a great consensus in the AAC community about what does not work when assisting in the language development of young children, there is very little consensus about what does work to assist in the language development of young children who require AAC (Beukelman & Mirenda, 1998). Children who learn language with the assistance of AAC utilize different modes in learning to communicate (Bedrosian, 1997;

Marshall & Goldbart, 2008). They utilize some of the same prelinguistic modes of learning as all other children including pointing, gestures, and noises, but they have the added linguistic modes including symbols, pictures, and graphic symbols such as Picture Exchange Communication Symbols (PECS) or Bliss symbols (Bedrosian, 1997). In most typically developing children, prelinguistic modes of communication disappear as the child becomes more proficient in the use of linguistics. Children who have significant language impairments may continue to use a combination of prelinguistic and linguistic language skills for communication. For these children, the use of some type of AAC device can promote communication while improving the child's language skills.

There is also one school of thought that states that the use of AAC might inhibit the development of speech in some children who use it (Millar, Light, & Schlosser, 2006). However; in their literature review of 23 articles that contained research on children with developmental disabilities and significant language impairment, the authors explored the use of AAC and information about speech production in the subjects before, during, and after implementation and found no evidence to support the inhibition of language development. Contrarily, Millar and co-researchers determined that 89% of the subjects in these studies demonstrated an increased ability to speak after the inception of the AAC device, thus providing important preliminary information about the impact of AAC on speech development.

Every language is composed of six domains: speech acts, pragmatics, phonology, semantics, morphology, and syntax (Beukelman & Mirenda, 1998). The capabilities of children who utilize AAC for communication may be somewhat more delayed than that of their typically developing peers even though the six domains of language development

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remain the same. Previous studies have indicated that children who utilize AAC devices have delayed function in the all of the domains. That is due in part to the fact that it is difficult to learn the correct principles of language when one is unable to speak the language. According to Vygotsky (1989), children learn from those persons around them, and persons proficient in the use of AAC like American Sign Language or even the use of a SGD are limited by the functions of the AAC method being utilized. Rules of language for children who learn sign language or who utilize PECS are distinctly different from rules of language for children who speak (Beukelman & Mirenda, 1998). This difference in language learning may lead to difficulties in the child being able to express multiple word statements (Binger & Light, 2007) as many of the AAC devices allow only for single word messages.

It is not uncommon for children with significant disabilities to have delays in both expressive and receptive language. The degree of impairment is one of the factors in the decision of the appropriate AAC method. However, there is a small group of children who utilize AAC who do not have delays in expressive and receptive language; these are children that have impaired speech due to injury or disease that does not affect their cognition. They express themselves very eloquently by using their device and/or the written word and have demonstrated an understanding of the rules and intricacies of language, even if they are unable to speak it, and they want to share language with others (Joyce, 1993; Marshall, 1994). Certainly for most children who utilize AAC, the development of language is complex and often frustrating (Bedrosian, 1997), but if the appropriate time, care, and instruction are provided, the newly found ability to

communicate can open up new avenues of life for the child who utilizes AAC and his/her family.

Family and Child Experiences with AAC

The children most likely to receive a recommendation for an AAC device are those children whose cognitive abilities far exceed the child's ability to communicate (Ko et al., 1998). However, the cognitive abilities of children are separate from the child's family life and should be considered separately from the stressors and cultural factors that influence the lifestyles of families of children with special needs (Cress, 2004; Parette & Angelo, 1996; Parette & Huer, 2002; Parette & Vanbiervliet, 2000; Vanbiervliet & Parette, 2002). Parental involvement is considered to be an important variable to all aspects of the successful use of AAC, but the requirement for parental involvement may inadvertently lead to greater stress for the parent/primary caregiver (Marshall & Goldbart, 2008; McCord & Soto, 2004). Stressors include the concern for the survival of the child in many instances, the increased time needed to insure that the device is programmed correctly as well as the time needed to practice the use of the device with the child, and the fear that the child will never learn to communicate effectively (Angelo et al., 1995; Dyson & Fewell, 1986; Jones et al., 1998).

One study that provided negative parental perspectives was conducted by McCord and Soto (2004). This small ethnographic study of four Mexican-American families whose children were learning to use AAC devices suggested that these devices were not perceived to be beneficial for useful interactions between family members. Family members also did not identify improved communication with the use of the AAC primarily due to language barriers and cultural preferences for speed and fluidity of

language. All four of the families did recognize the importance of AAC as an educational tool, but they did not believe that the use of the AAC made a positive impact on life within the family unit.

Even though there are a number of stressors and negativity associated with the use of any new technology within a family, the positive effects will usually far outweigh the negative effects (Jones et al., 1998). Children who learn to become communicative have fewer behavioral issues, increased attention, increased self-confidence, and are able to participate more actively in family life (Silverman, 1989). That is not to say that even these positive effects do not have a profound effect on not only the child, but all of the family members as well (Angelo, 2000). There is very little literature that investigates the exact effects of the introduction of an AAC and the resulting changes in the child's communication abilities on other members of the family. The three studies identified will be reviewed in detail below. As with other areas of AAC research, much of the current literature is anecdotal in nature (Marshall & Goldbart, 2008).

The first of these three studies was conducted by Jones and co-researchers (1998) to determine the needs, priorities, and preferences of parents in regard to their child's use of an AAC device. A total of 59 families were represented (56 mothers and 35 fathers). Results were analyzed using descriptive statistics. The mothers and fathers responding to the survey indicated two common priorities. Fathers indicated a strong need for increased knowledge related to the device. Planning for future communication needs was identified strongly as a priority by both mothers and fathers. However, it was noted that mothers and fathers identified different priorities in relation to the AAC, so it is important to insure that all significant family members be allowed to participate in the identification of

priorities of the child's AAC device. It is important to address all of the family issues to insure the successful use of the device.

Angelo (2000) conducted a survey of parents of children attending Pennsylvania schools, who were also utilizing AAC provided through the long-term equipment loan program of the Central Instructional Support Center. Of 500 surveys originally sent out, only 114 parents (23%) responded. The survey contained 76 impact statements using a 5-point Likert scale. More than half of the participating subjects indicated an increase in responsibilities due to device-related roles and responsibilities as well as an increased demand for personal time related to the AAC device. More than 60% of respondents reported a positive attitude toward the use of the AAC device and indicated that the AAC users were better able to express both positive and negative emotions, and demonstrated improved physical and emotional well-being.

In their 2008 study, Marshall and Goldbart, interviewed the families of 11 children in Great Britain who were in the early stages of learning to use any type or combination of AAC devices. This qualitative study utilized semi-structured interviews to investigate how the use of the AAC device has impacted the life and communication abilities of the child and family. Thematic analysis was utilized to gain a perspective of the "lived experience" from the gathered data. The parents indicated that all of the children requiring AAC in the study utilized more than one method of communication, with the most commonly reported mode of communication being used as British Sign Language. Seven of the 11 children also had access to a high technologic device such as a SGD. Three primary themes arose from the research: child's communication and interaction, wider societal issues, and parent's views and experiences. The conclusions of

the study identified parents as the experts who understand the child's ability to communicate using multiple modes of communication assistance. The study also supports the use of individualized assessment and intervention as the use of AAC is not "one size fits all." The use of AAC is dependent upon the child's cognition, physical abilities, family supports, and the ability of the child and family to participate in adequate training sessions to insure the successful implementation of the AAC technology deemed most appropriate for the child. Parents need fair warning about the time commitment required to insure the maintenance and upkeep depending on the type of AAC being used by the child. Cultural factors play a role in the acceptance or rejection of AAC as well. Differing devices may not be readily accepted into cultures that pride themselves on the speed and fluid construction of language as AAC devices may not allow for the required speed and fluidity.

There is a profound lack of research involving attitudes and experiences of children who are learning or have learned to use a communication device. Currently no qualitative studies have been conducted to explore the lived experience of the child as he/she learns to communicate using an AAC device. Most of the current research addresses the special needs of utilizing AAC with children who have significant intellectual and developmental disabilities (Bedrosian, 1997; Light et al., 1985; Wilkinson & Hennig, 2007), or ways of promoting interactions between children using AAC and their peers (Beck & Fritz-Verticchio, 2003; Johnston et al., 2004). Vygotsky (1978, 1989) contends that cognitive development occurs during social interaction with other persons within the child's environment. This can be a combination of friends, acquaintances, strangers, children, adults, and/or teachers (Renner, 2003; Siegler &

Alibali, 2005). These interaction and subsequent communications are very influential in the child's development. Children who are unable to speak due to illness or injury remain on the fringe of social interaction due to the inability to effectively communicate. Many sociocultural theorists believe that thinking and behavior cannot be separated from the social context in which they occur. According to Vygotsky (1978), developmental change occurs when there is internalization of shared experiences; therefore, it is essential to find a way to assist children who are unable to speak due to illness or injury to find a voice to enable them to communicate with their able-bodied peers. Children who have never encountered a peer who uses an AAC device may lack an understanding of the purpose of the device. Beck and Fritz-Verticchio demonstrated that children who are provided with information about the device and who are allowed to participate in role-playing activities are better prepared to accept the use of an AAC device by one of their peers than children who have no knowledge of the device.

In their 2001 study, Clarke and co-researchers investigated views of children and young persons who were utilizing AAC devices for communication. Six young adults and 17 children participated. Focus groups were used for the initial informing about the study and to set up the individual interviews, but individual interviews were utilized to ascertain the views of each participant. Most of the children interviewed indicated that the method employed was useful to them in most situations, but there were also some negative views related to the skills needed to utilize the device, self-concept issues due to the need for the device, and a lack of perceived benefit for interacting with others.

A different kind of study conducted by Light, Page, Curran, and Pitkin (2007) asked six typically developing children to develop ideas to assist children who were

unable to speak to communicate more effectively. The designs proposed by the children were significantly different than currently existing AAC designs. The devices proposed by the children integrated more functions including "communication, social interaction, companionship, play, artistic expression and telecommunication" (p. 1). In essence the children were trying to provide their counterparts with a disability some of the same opportunities for communication afforded to them. By incorporating the ideas of the children, AAC technologies could become better accepted both by the child who requires the use of the device and his/her able-bodied peers.

Summary

Research involving the use of SGD has increased in the past few years; however, many gaps remain in the literature. Most studies focus on AAC technologies as a whole and do not examine the use of a SGD as a separate entity. Children who have the support of their families have the best outcomes when learning to use SGDs, but there is no research that examines the impact of the device on all members of the family. It is known that there is a high abandonment rate of AAC devices among children with disabilities who require them, and there is beginning understanding about why parents may not encourage the child to use the devices, but there is no clear understanding of the costs associated with SGDs or how the length of time it takes to obtain the devices affects the development of the child (Crisp, unpublished pilot study). Even though there has been an increase in research surrounding language development in children who require a SGD, there remains a lack of understanding about the language differences in children learning to use SGD language compared to children with typically developing language. Another

identified gap is that much of the current research has been conducted with children who are typically developing and not children who actually require the use of a SGD.

A number of studies identify a lack of professionals available to support children and families learning to use a SGD, but none of those studies identifies the role of the nurse as a potential support for these children and families. Cultural barriers to the use of a SGD have also been identified. Most SGDs are not capable of providing the quickness and fluidity present in some languages. Current studies with adults indicate a need for better devices to meet the needs of persons who are temporarily ventilator dependent and more sophisticated devices with better telephone capabilities for those adults requiring a SGD for longer periods of time. Research with adults using a SGD cannot be easily translated to children as most of the adult populations that have been studied have disorders that disable them later in life when language has already been learned prior to them losing their ability to speak.

Conclusions

The studies presented here indicate that there is a strong need for family education and support for the successful implementation and continued use of SGDs by children who are unable to speak. While there has been an increase in the research being conducted with children who require a SGD and their families, much more research needs to be conducted to determine the effects of the use of SGD on the child and family members. Only one study was found that actually investigated the lived experience of beginning to use AAC methods, but none of the current research investigates the lived experience of the family of the child who uses a SGD. Research conducted with children

and young adults who require the use of a SGD is sadly lacking and is in need of further exploration.

More research is needed if we are to gain a true understanding of the impact of a SGD on the children and families who require them. Qualitative research methods such as those inspired by the work of Heidegger are one way to gain an understanding of what it is actually like to live in the family of a child who uses a SGD. This information is needed for families of children who might be considering the use of a SGD as well as for the professionals who assist in the choice and training in the use of the device.

This research study was conducted to examine the experience of having a child who uses a SGD through the eyes of the primary caregiver. By examining the experience of the family, new insight has been gained about what it is like to have a child who is learning to use a SGD; how to best support the child and family to prevent abandonment; and what kinds of educational experiences are needed for all support people working with the child and family.

CHAPTER THREE

Methods

As stated in Chapter one, the purpose of this study was to give a voice to the

experiences of families around a child's use of a SGD by analyzing family experiences of

the child's use of a SGD as seen through the lens of the primary caregiver.

Design

Interpretive phenomenology, influenced by the work of Martin Heidegger, was

the guiding principle that was used to illuminate the meaning and significance of the

lived experience of the family of a child who uses a SGD as seen through the lens of the

primary caregiver. Primary caregivers of children who use a SGD were interviewed to

determine their perceptions of what it is like for the family as the child is learning to use a

SGD. Interview questions were asked to elicit responses that describe the lived

experience of the journey for all identified family members.

Interpretive phenomenology provides a method for sharing the stories of families

who are living with a child with special needs. This is due in part to this type of

qualitative research considering that all persons existing in the world exist in time and

place in which certain things and processes are culturally significant (Crotty, 1996;

Kerney & Griffin, 2001). In other words, we are one with the world and have all of the

learned experiences of our lives and our cultures to use to develop our own thoughts and

ideas. Interpretive phenomenology allows the families to share their stories with an

interested researcher who then interprets what has been said and shares it with the world.

In my experience, there is none of the silence or discomfort that is experienced when

speaking with friends who do not have a child with a disability. Interpretive

phenomenology also provides a venue for parents of children with special needs to voice their experiences, thoughts, and ideas in a non-judgmental way, thus providing society as a whole with a better perspective of what it is like to parent a child with special needs who is learning to use a SGD.

The internet has opened up a new avenue for conducting research. The features present on the internet allow interviews to be conducted in a manner similar to the face-to- face interview, focus groups, and surveys. Some internet services even allow for the use of cameras so that the interviewer and participant can see each other (Davis, Bolding, Hart, Sherr, & Elford, 2004; Mann & Stewart, 2000). Internet recruitment is particularly useful when the population being investigated is small and spread out over a large geographic area. Internet research can decrease travel costs, time investment, and sometimes, transcription costs (Davis et al., 2004). Certainly internet recruitment does not allow for the recruitment of that part of the population who is not computer savvy or for those families who do not have internet access, but in my previous study I discovered that the majority of families whom I interviewed and who have a child using a SGD have sufficient knowledge of and access to the internet as it is an important component in training the family on the use of the devices.

There are several internet services available that allow for recruitment of study participants. SKYPE, an encrypted internet telephone/teleconference network, was used to conduct interviews with two of the participants recruited from the list-serv. The download is free to all internet users (http://www.SKYPE.com), and has a purchasable companion piece called PAMELA that records all conversations conducted through the telephone network. SKYPE also provides opportunities for conducting audio-taped, on-

camera interviews via a secure internet access, which allows for internet users to both see and be seen by the interviewer, making the interview more like a face-to-face meeting than a traditional internet interview. The ability to see and read the expressions of the participant can sometimes be an invaluable tool for the researcher as it provides the piece missing by voice communication alone.

Participants

The target population for this study was adult primary caregivers of children who are currently using or have previously used a SGD. This population was selected because they were the most available population to me in the pilot study. As my work in this area continues and relationships with these families evolve, I hope to be able to interview all members of the child's extended family to explore their experiences. Purposive sampling technique with snowballing was used to recruit 11 primary caregivers. The two mothers recruited from Colorado received a copy of the autism newsletter from someone that they knew in a different state. Participants were chosen based on their willingness to participate in the study and share their story as well as their ability to communicate effectively in English, and their willingness to take the time to participate in the study. One mother who made contact about the study withdrew her original interest when her son experienced some significant health changes.

Inclusion criteria were that the participant was the primary caregiver of a child who had previously or was currently learning to use a SGD and who are able to communicate effectively in English. All participants in this study were the mother as well as the primary caregiver of a child learning to use a SGD. These mothers identified themselves as the primary caregiver even though other family and hired caregivers were

involved with the child. Caregivers of children using other AAC methods as a sole method of communication and not using a SGD were not included because alternative methods of AAC are experienced differently.

Procedures

Subjects were recruited through the newsletter for a not-for-profit organization that provides support services to families of children with disabilities, the local autism newsletter, and a widely used public list-serv on the internet. The student investigator is a member of the board of directors of the not-for-profit organization and is a participating member in the list-serv. A letter introducing the study, listing study requirements, and including study contact information was distributed to the not-for-profit and autism newsletters and in an email to all list-serv members. Interested parties were encouraged to contact the student investigator by telephone or email to obtain further information about the study. To provide for confidentiality, all contacts were made to a cell phone dedicated to the study or to the investigator's private email account. The initial contact with the student investigator included an explanation of the study. Once the study had been explained, questions answered, and the caregiver agreed to participate, the interview was arranged for a date and time specified by the participant. Although the possibility for in-person interviews was available, all of the mothers chose to either be interviewed using SKYPE or via the telephone. Written consent was obtained prior the interview.

Each interview lasted from 30-90 minutes and was audio recorded or audio recorded via SKYPE/PAMELA for accuracy of data collection. Demographic information such as race/ethnicity, gender of the child, gender of the caregiver, age of the child, how long the child has been using the SGD device, type of device, number of

people in the family, number of people assisting the child with the device, and educational level of the child and primary caregiver were collected. Because 6 of the mothers know each other, only minimal descriptive data will be shared in an effort to maintain anonymity. Field notes including information pertaining to the study, such as setting, time of day, vocal inflections, facial expressions, nonverbal communication, and gestures were also recorded. All participants were asked a very open-ended question such as "Tell me about your experience with use of your child's voice output or speech generating device" to stimulate the conversation. Other probing questions used for the initial interview can be found in Appendix A.

After the completion of the first five interviews, it was decided that even though some data were obtained, a review and revision of the study question and probes would perhaps elicit even more information. While the first five interviews yielded data visible to the pediatric members of the team, other team members struggled to find meaningful data. The broad question was revised to state "Tell me about when you first knew your child was going to need a communication device and how did you get from there to where you are now." This new question opened up a much richer conversation and provided excellent data that were revealed to all members of the team (see Appendix B for the amended list of interview questions).

All audio-taped and SKYPE-recorded sessions were transcribed by the student investigator. Transcriptions were de-identified to protect confidentiality of the participants. Pseudonyms have been used in place of names, and the names of facilities and locations have been removed or changed. Audio-taped interviews and transcripts

have burned to a CD and removed from the computer hard drive. Only de-identified data has been/will be shared during and upon completion of the study.

Protection of Human Subjects

Permission to conduct this study was obtained from the institutional review board of the large Midwestern University with which the investigators are affiliated. Permission to recruit from the newsletters and the list-serv were obtained from the directors of each entity. All risks and benefits were explained to potential participants during the intial contact with the student investigator. Meeting times and locations were chosen by the participants. All internet interviews were conducted on an encrypted internet phone service. Telephone interviews were conducted on a cell phone purchased specifically for the study to protect participant confidentiality.

Consent was obtained from each participant just prior to conducting the interview. A copy of the consent was provided to each participant. A typed signature and date were considered the same as a written signature and date for participants being interviewed via SKYPE. A faxed consent form was also accepted. Risks associated with the study were considered to be minimal. None of the participants verbalized or demonstrated any stress associated with the study. Participants were informed that they could choose not to answer any questions or that they could withdraw from the study at any time without penalty. Benefits to the study included sharing their story and knowledge about having a child using a SGD that can be used to help provide education and information to parents, professionals, legislators, vendors, and the community about how SGDs change the lives of the child and family who use them. Participants who completed the study received a

$25 gift card from a department store of the participant's choice as a token of appreciation for their participation.

There remains a risk for the loss of confidentiality for all participants, but strict measures have been taken to prevent a loss of confidentiality. All data are kept in a locked file cabinet in the student investigator's office. Participants have been assigned a study number: no names, other than pseudonyms have been attached to the data. Transcripts have been burned to a CD which is kept in a locked cabinet in the office of the student investigator. No hard copies of the transcripts have been kept.

Only de-identified data has been shared with the members of the Hermeneutic Circle, a group of experienced and novice researchers who each read and individually interpreted the data in an effort to prevent the researcher from being blinded to new revealing by what is already known. Even though no medical information was obtained, HIPAA guidelines for the protection of confidential information was adhered to throughout recruitment, data collection, data storage, data analysis, and dissemination of the study findings.

<div align="center">Data Analysis</div>

Interpretive phenomenology encourages the researcher to dwell with the data and become a part of the world of the participant to gain a better understanding of his/her experience (Benner, 1994). Vocal inflections, facial expressions, gestures, and other non-verbal communication were documented in the field notes along with any pertinent information regarding the setting and added to the transcript where appropriate (Crist & Tanner, 2003).

The hermeneutic process is dynamic and cyclical; it is not static or structured, and it is by no means a theoretical approach to interpretation, so attempts to describe it in written form are often inaccurate. According to Heidegger (1962), "any interpretation which is to contribute understanding must have already understood what is to be interpreted (p. 194)." Thus the circle has no beginning and no ending. Yet it does have the potential to move forward or backward based on our questioning. It is a part of our understanding.

This understanding is not static. The things that we relate to now may not be the same thing that we relate to tomorrow or the next day. New revealing can occur based on viewing the same data at different times or having different people review the same data. This idea of different revealing occurring to different people is the premise behind the development of what we call a Hermeneutic Circle (Moran, 2000), a group of researchers who each individually interpret the data. The explanation of the process used by the Circle helps provide a description of how the narrative accounts of this current study were analyzed. The discussion also provides a roadmap that allows others to follow the multifaceted road to this kind of thinking (Diekelman & Ironside, 1998).

Based upon the roadmap presented by Sloan (2002), analysis occurs in three moments. The first of these moments begins prior to and beginning with the interview. This initial and immediate interpretation allows the interviewer to ask more questions and seek clarification of thoughts as needed (p. 130). As the interview progresses, the researcher may need to ask different questions or request clarification to insure that what is said and what is heard are the same. Field notes are also important. Things such as the participant's manner, timely or untimely arrival for the interview, appearance, and

attitude may provide a completely different picture than the one being revealed in words. Without the use of field notes, some of the meaning of the interview could be lost.

The second moment begins with the transcription of the interviews including the information taken from the field notes. Each interview was transcribed verbatim by the student researcher from the originally recorded interview shortly after the interview took place. Each transcript was then compared with the originally recorded interview for accuracy by the student researcher.

The researcher read through the transcript and highlighted passages that were considered to be meaningful, important, interesting, or something that had not been noted in previous or other interviews. The transcript was then set aside for a while to allow the student investigator to dwell with the data prior to repeating the same process to see if the same things stood out again, to determine if the investigator was able to find new meaning in some of the passages, and to determine which of the actual stories defined the experience. This setting aside and revisiting the transcripts continued throughout exploration of the interviews and was only finished when all of the meaningful data have been gathered.

Once these initial interpretations were completed, the original transcripts and initial interpretations were shared with the members of the Hermeneutic Circle (Moran, 2000), a group that includes an instructor experienced in this method as well as the primary investigator for this study and graduate students learning to use this method. This shared interpretation was used to reveal commonalities and shared experiences among family members who have a child who is currently using or has previously used a SGD. Each member of the group read each text and identified those statements and ideas that

stood out or illustrated the meaning of what the lived experience is like. Each circle member presented their identified themes with supporting passages from the text during the team meetings and presented these as a gift to the student investigator. All interpretations were read aloud with the appropriate time set aside for questions and discussion. This process helped to eliminate any bias on the part of any member of the group.

All subsequent interview texts were transcribed and analyzed using the same team process. As new themes came to light and previously identified themes became more refined, the interpretation became more complete. Emerging themes were recorded with the supporting text to ensure that the themes were accurately represented.

The third moment of interpretation took place when the narratives were evaluated as a group of narratives. This allowed for the examination of patterns and themes across all of the narratives to see if the same or different patterns and themes occurred. The student investigator additionally reviewed all pertinent literature to identify the gaps that in turn were used to help with interpretations. This was a concurrent review occurring at the same time as the interpretation of the texts. This constant review of the literature provided information to help in defining the emerging themes from the ongoing interpretations. It also provided additional comprehensive depth to the interpretations and provided a method to define contradictions arising from the texts.

This continual review of the transcribed interviews and current literature allowed the student investigator to remain immersed in the data. By applying current literature regarding the use of a SGD, symbolic interaction, and literature describing family use of assistive technology, the student co-investigator was provided with a very rich analysis of

all the existing data leading to a deeper understanding of the lived experience of the child's and family's journey to communication.

Continuing conversations with the Hermeneutic Circle aided in the elucidation of the most accurate and meaningful interpretation. These interpretations are always situated in history, politics, and personal biases (Ironside, 1997); thus each interpretation is as much of a snapshot in time as the original transcript. The identified themes are not absolutes and are not to be considered as the "only truth." They are a way to guide the reader to the general vicinity of the lived experience. There is not one true interpretation of the original text, and it is important to remember that interpretation is not boundless. The population of interest establishes limits and boundaries for research based on their own prior knowledge and experiences. This is controlled by them in part by the information they chose to share with the researcher. The investigator is only privy to as much of the lived experience as the participant is willing to share. Hermeneutic phenomenology does not provide explanations of individual experiences. Instead, it provides the reader with a way to understand the experiences of the child and family who have learned to communicate using a SGD.

<div align="center">Rigor</div>

The assessment of rigor, for lack of a better word, in qualitative research studies remains a controversial topic even by those who practice in the field (Crotty, 1996; deWitt & Ploeg, 2006; Horsburg, 2003; Mill & Ogilvie, 2003; Porter, 2007; Rolfe, 2006; Tobin & Begly, 2004). Even the term used to describe rigor cannot be agreed upon. Some call it trustworthiness, some rigor, and others validity. One of the reasons for this is that qualitative research is not concrete; meaning is never stagnant, it is always moving, so to

stop and take something out of context could lead to a change in meaning. Rigor is not something that happens when the study is completed. It is built into the Hermeneutic process every step of the way. Some would argue that there is no need for rigor in qualitative research while others continue to strive to find a very definitive way to establish rigor. For the time being, there are several schools of thought. The one that I have chosen for this study is the one proposed by deWitt and Ploeg (2006).

These authors conducted a critical review of all the interpretive phenomenological nursing studies published from 1994 to 2004 to explore the methods of rigor identified in these studies. Using this information they offered a proposed framework containing the following five expressions: balanced integration, openness, concreteness, resonance, and actualization. The first two expressions address the research process and the remaining three address the research outcomes

Balanced integration is described as providing a discussion of the philosophical underpinnings and how they fit with the research and subject being studied, an intertwining of the philosophy throughout the methods and findings, and a balance between what is revealed by the study participants and the use of philosophy to explain the findings. Madison's (1988) proposed criterion of comprehensiveness has also been integrated into this expression. Madison used the term comprehensiveness to define the relationship between what is being interpreted to the interpretation of the work. In other words, the primary tenets set forth by the philosopher must be present in the researcher's interpretation.

The second expression proposed by deWitt and Ploeg (2006) is openness, a nice fit when one is using Heideggerian phenomenology as Heidegger identifies openness as

part of Being. A researcher who remains open is able to explain every step taken along the path from the inception of the study throughout its completion. Any other researcher would be able to read the process taken and know how and why decisions were made throughout the study and could re-create a similar study if necessary.

The third expression is concreteness, even though meaning is not concrete because it is everchanging. This expression is a combination of usefulness, contextuality, and linking the interpretation so that others are able to identify an interpretation within the understanding of nursing practice. Usefulness seeks to define how the findings can be used throughout the practice of nursing. Contextuality describes reading the author's work in consideration of the historical and cultural contexts in which it is written. Personally, I prefer the terms usefulness and contextuality due to the fact that by process definition alone, Heideggerian hermeneutics are not concrete because meanings are ever-changing and can be different at different times of interpretation even if remaining true to historical and cultural contexts.

The fourth proposed expression of rigor is resonance. This term describes what is felt by a reader who becomes engaged with the research. It is that understanding of the interpretation of the revealing of information that has been previously concealed and how it affects the reader as an individual as well as the population in general.

The final proposed expression is actualization which examines the future resonance of the study findings. As stated earlier, the interpretation does not end with the completion of the study. It is ongoing and will continue to be interpreted by anyone reading the interpretations in the future.

Even these proposed expressions contain limitations, partially due to the way the expressions are named and how those names are defined by individual researchers. The word concrete indicates no motion and by the definition alone suggests that meaning stops with this single interpretation and that future interpretations might not be possible. This lack of exact, definitive expressions allows for a lot of self-interpretation as to whether rigor is met or not. This could be, and often is, extremely confusing for new researchers entering the field.

This explanation of the expressions of rigor suggested by deWitt and Ploeg (2006) does not provide a solution to the controversy surrounding the assessment of rigor in qualitative research; however it does provide another way of assessing rigor that may be desirable for some researchers. It is very apparent that a consensus about the criteria of rigor may not occur for some time to come, but it does help to bring together some of the previously identified criteria and presents them in a way that is more usable and easier to understand.

Summary

This chapter provides a brief discussion of the methodology of interpretive phenomenology which was used to guide this research. Participants were recruited using purposive sampling with snowballing from two newsletters for parents of children with special needs and an internet list-serv for parents and users of AAC. Study approval was obtained from the IRB of a large Midwestern university. Precautions were taken to protect the privacy of the participants. The materials used in the study as well as in the collection of data were discussed.

Interviews were conducted via SKYPE, an encrypted internet telephone service, or via regular telephone. Each interview lasted 30-90 minutes. The probes were revised after the fifth interview to elicit more information. Once the interviews were completed, the interviews were transcribed verbatim and shared with members of the Hermeneutic Circle for interpretation. Each member of the circle read each interview and presented their interpretation as a gift to the researcher. Themes and patterns were identified in individual interviews and across all interviews. A second literature review was conducted to help provide clarity to the interpretation. Continuing conversations with members of the Hermeneutic Circle helped to elucidate the most meaningful and accurate interpretations.

A brief discussion of rigor in qualitative research was presented along with some limitations and strengths of a recently proposed framework for the assessment of rigor in nursing literature. Rigor remains one of the most debated topics in the field of qualitative research and continues to undergo evaluation and critique and no single method for evaluating rigor has been identified.

CHAPTER FOUR

Data Analysis and Interpretation

Introduction

Hermeneutic phenomenology seeks to reveal what has been concealed. Heidegger (1962) stated "Discourse is the meaningful discourse of the understandable structure of being-in-the-world" (p. 204). Being-in-the-world is never fully defined by Heidegger, but according to Guignon (2006, p. 11), it is how our everyday contextual experiences are inseparable from our practical everyday involvements in the world in which we live. Basically it is our understanding one's self and the world in which one exists. By interviewing and interpreting the narratives of primary caregivers who have a child who uses a SGD, the researcher is able to gain an understanding and practical knowledge of what it is like to live in this world. Because the knowledge that we uncover is influenced by what we already know, it is important to investigate previous studies in the realm of AAC to gain a true understanding.

Helen Keller was the most famous early user of augmentative communication. Her education in and use of sign language for communication is well documented in books, theatrical productions, and the movies. *The Miracle Worker* (Coe & Penn,1962) starring Patty Duke is actually the story of Helen's teacher, Annie Sullivan, who worked diligently to find a way for Helen to communicate. In her book, *The Story of My Life* (1903/2003), Helen describes the moment when she first connected concepts and words:

> As the cool stream gushed over one hand she spelled into the other the
> Word *water*, first slowly, then rapidly. I stood still, my whole attention
> fixed on the motions of her fingers. Suddenly I felt a misty consciousness
> as of something forgotten—a thrill of returning thought: and somehow
> the mystery of language was revealed to me. I knew then that"w-a-t-e-r"
> meant

the wonderful cool something that wasflowing over my hand. That living word awakened my soul, gave it light, hope, joy, set it free! There were barriers still, it is true, but barriers that could be swept away in time

(Keller 1903/2003, pp. 27-28).

Like Helen, many children with developmental disabilities are silent. They are robbed of speech; however, their silence speaks volume. As Diekelman (2009) so eloquently said "the lack of speech itself is a way of speaking. Being silent is a call, a breakdown, where people incapable of speech show up." These children have so much more inside, just like there was with Helen. Just because a child is unable to speak does not mean that he/she is unable to think, feel, understand, and participate. Children who lack the ability to speak just need to find a connection between the word and the understanding to enter a world in which communication becomes possible. The sojourn into the world of language and communication belongs to both the child and the family. All members are affected by living in the world the way it currently exists. The ready-to-hand method of communication for those who are able to speak remains unready-to-hand for the child who requires a SGD. It is not only the child that experiences these difficulties. Heidegger, simply stated, describes ready-to-hand as the way one gets along in everyday life. When there is a breakdown or something interferes with the way a person gets along in the world, the situation is unready-to-hand (Ironside, 2009). In this world in which technology is readily available to most everyone, people have come to expect that whatever is needed will be ready to use whenever it is needed. This is not so for the child who requires someone to set up the SGD, program it, and perhaps even hand it to the child.

Because of this need for the use of the device in an unready-to-hand world, the child and family must undergo many changes between the initial SGD evaluation and the

time the child and family become proficient in it use. The metaphor of metamorphosis is one way to describe these changes.

The Metaphor

As my daughter progresses in school and enters the realm of science, we are encountering a plethora of new experiences. One of these involved watching a caterpillar go through the stages to become a butterfly. After watching this metamorphoses from caterpillar, to chrysalis, to butterfly, I realized that this is the same process that children and families go through as they learn to use their SGD. The change from a child and family who are unable to communicate effectively to a child and family who are able to communicate well with the world is huge, just as the caterpillar becoming a chrysalis, a cocoon where the changes needed to transform from a caterpillar to a butterfly occur, is huge. Thus the metaphor of metamorphoses was revealed to me. The metamorphosis of the butterfly begins with the caterpillar, so does the metamorphosis of a child who is learning to use a SGD.

The Happy Caterpillar

Once upon a time
a tiny striped caterpillar
burst from the egg
which had been home for so long.

"Hello world," he said.
"It sure is bright out here in the sun."

"I'm hungry," he thought
and straightaway began to eat
the leaf he was born on.

And he ate another leaf…and another…and another…
And got bigger…and bigger…and bigger.

Until one day he stopped eating
and thought,
"There must be something more to life
than just eating and getting bigger."

"It's getting dull."[1]

This poem is part of a story called *Hope for the Flowers* which tells the story of two caterpillars and their experiences with the world. One of the caterpillars searches high and low for meaning in life, while the other is slow and persistent until one day she becomes a butterfly reuniting with her caterpillar beau and leading him to the life of a butterfly. Children who are unable to speak are very much like a caterpillar that is happily crawling along, eating, and observing, until one day, they want more!

The desire to communicate is expressed in many ways. The child will point, use gestures, speech approximations, make guttural sounds or use picture/word displays--all in an effort to get a message across. Unfortunately, many children also express frustration and anger when they are not able to make their thoughts and ideas known. The child may also have behavior issues related to the inability to communicate effectively. Below, Mona describes how Katie's behavior changes when she is unable to communicate what she is thinking and feeling.

> You know honestly, the biggest thing, I think for Katie, would be that I
> Hope it gets rid of some of her frustrations. Her frustration level is out of
> the roof. I mean she is a hitter, a kicker. I mean she just has these horrible,
> horrible fits of frustration, and she is trying to tell me something.

It is not uncommon for children without speech to have difficulty expressing feelings, emotions, pain, and other abstract concepts. They oftentimes have to keep the

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[1] Note: From *Hope for the Flowers* by T. Paulus, 1972, Paramus, NJ: Paulist Press. Copyright 1972. Reprinted with permission.

pain inside because there is no way to express it other than action. Sometimes the silent

pain becomes physical as described by Mona.

> Also, she doesn't tell me if she doesn't feel well, or if she is sick or
> hurt. She doesn't have a way to tell me. When she has a runny nose, I
> know. She doesn't feel good, but there are other times when she is just
> grouchy.

Mona is able to recognize when her daughter does not feel well when physical

symptoms are present. However, the symptoms only tell her that her child is sick, not

how she is feeling. Emotions remain in the absence of speech, so it is very important to

find a way to allow the child to express the emotions to have a true understanding of what

may be upsetting the child. The following excerpt tells of a mother's frustration at being

unable to comprehend why a song upset her daughter.

> I don't know if you know the song *I am beautiful* (sic) by
> Christina Aguilara. It's basically, "these people don't think I am, but
> I know that I am". I like the song because I think it is very powerful.
> "I don't care what you say, I'm a good person, you know, I am
> beautiful." and Julia just started crying, just inconsolable crying, and
> we were driving, so I didn't have an opportunity to get her device out
> to say "is there anything on your device that can tell me why you are
> crying": and we had to turn the music off, andshe won't listen to that
> song.
>   We've tried the talker to see if there are words that she can
> tell me about what it is about the song that bothers her, but we can't find
> the words, and I do know (very tearfully) that there are words inside her.
> You know, she has no way of telling me. So one of the great mysteries of
> life is why this song is so disturbing to her.
>
> <div align="right">(Ruth)</div>

"One of the great mysteries of life is why this song is so disturbing" to this young

girl. What an eye-opening statement! Most parents take for granted the ability to talk with

their children to find out what may be upsetting to them. This mother, who knows her

child so well, is unable to understand what it is about this particular song that is upsetting

to her child because words are needed to help guide the understanding of why the song

bothers this teenager. Since I was unfamiliar with the song, I looked up the words. The

song is entitled *Beautiful* and the lyrics say;

I am so beautiful, no matter what they say
Words can't bring me down
I am beautiful, in every single way
Yes, words can't bring me down
So, don't you bring me down today

(Perry, 2002)

These are very powerful lyrics when taken in context with a teenager with

developmental disabilities. Julia's inability to speak impedes her abilities to explain

exactly why the worlds of the song are so upsetting to her. Any understanding on the part

of her mother is conjecture. Without the ability to use her SGD, Julia has no effective

means to communicate her thoughts, ideas, and emotions.

There comes a time when ineffective means of communication are not enough for

either the parent or the child. The words must find a way out. The desire to communicate

and to be understood become paramount, but SGDs may not be right for every child.

Evaluations and device trials become imperative in insuring that the child receives the

appropriate method of AAC for him/her. For many children, language comes using

multiple methods, such as sign language, gestures, and the use of the SGD. Nan describes

the multiple methods of AAC used by Kyle in his home.

> So instead of using a single method of communication, he uses a
> combination of manual sign, digitization, and light tech options. After
> he first gets up, he goes to the bathroom: he has a Light Tech screen in
> the bathroom. He gets dressed, and then he comes downstairs. When he
> comes downstairs and gets in his wheelchair, he gets his talker. He calls
> it his talker because it SPEAKS (exaggerated word) for him. So, we use
> that in combination with Light Tech, manual sign, and gestures.

Kyle uses many methods of communication in his everyday life because not every

method is available to him during every part of his day. Parents have learned to be very

creative in ensuring that their child is able to communicate "where *they* are" and not just

when the child is in a social setting. Whatever method of AAC that is being employed by

a child at a given time must be ready-to-hand, or readily available for the child's use.

Ruth describes how she found a way to make communication available for her toddler

who was unable to speak.

> …we had plastic covered Mayer Johnson symbol pages all over the
> place. I velcroed them to the cabinets so that when she crawled by,
> she could point to something. We had them all over the place so that
> someone that was crawling could get to them. Our house looked kind
> of funny, but that worked,and we began an early type of sign language.

This innovative mother found a way to help her toddler begin to communicate:

however, the symbols needed to be at the eye level of the child, so that she could reach

them when she wanted something. These stories also help to demonstrate how unready-

to-hand that AAC can be. The method of AAC has to be available for the child to access

it before it can be useful. Velcroing Mayer-Johnson symbols to everything worked well

for this child, but someone had to take the time to hang the symbols and someone had to

set up the Light-tech system in Kyle's house; all of which are not required for people who

are able to speak. Even though the situations described are not ready-to-hand, the stories

do help to describe how important it is for the child to be engaged and to engage others in

his/her world so the task of learning language can begin. Many children begin to learn

very quickly when they are allowed to participate in the world around them in a new way.

The child may even learn some problem-solving skills to help him/her communicate

more effectively. Marsha describes how Katie made her mother aware that the current

method of AAC was not the appropriate one for Katie's communication needs.

> So we brought one home [a simplistic communication device] and it took
> maybe two days before she was signing; she was using it and she was

asking for something. I think it was a drink and what she wanted was not in there, so what she did was get right next to the side of the Cheap Talk, where she would have expected the spot to be, she got down and signed right next to that, so not only was she telling me, I want whatever it was, I think it was a yogurt drink, but she was also quite clearly telling me that this is not enough for me because this should be over there.

This story demonstrates how creative a child can be in trying to communicate her wants and needs to those around her. It also helps to show that not every device may be appropriate for every child, and because no one device or method is appropriate for every child (Williams, 2006), finding the appropriate AAC specialist may be difficult and time consuming. A few AAC specialists are familiar with a variety of AAC methods, while others specialize in the use of only one type of AAC device or devices made by only one vendor. This can be problematic when the devices with which the AAC specialist is most familiar are not the best device for the child being evaluated. There may also be preconceived notions of the child's abilities based on the child's diagnoses, which may in fact be extremely erroneous. Marsha describes her frustration with getting an evaluation for her daughter.

I felt, that having talked with other parents, that sometimes there is a tendency to recommend what a speech professional is already familiar with as opposed to really taking it as a full evaluation perspective, …so we actually ended up getting in for an evaluation which was absolutely disappointing…I spent an hour, a little bit more than an hour with the whole team thatwas going to be evaluating her, telling them about where we had been, what her motivations were,what her motivating situations were, what turned her off, what engaged her, what doesn't, what she has right now and how she was doing with it.
When I got there, there were four, one was the Springboard Lite, which I don't think they even make anymore, the second was another PRC device where you had to record everything,…I had already told them I won't be doing that for her, she already has us to interpret sign for her, so I don't care if it sounds like a robot, I want her to have herown voice, 100%, so that when she hears it, she knows it is something that she is saying and not intertwined with something that I am saying….

The process to get the right device may be long and frustrating. As Marsha describes, the evaluation may not always be geared to assess the child in the manner needed to find the best device for the child, but once the right device has finally been obtained, the child and family are ready to begin the transformation from caterpillar to butterfly by entering the chrysalis of silence, where learning to use the device really begins.

<p style="text-align:center">The Chrysalis of Silence</p>

Once the child receives the SGD, he/she moves into the chrysalis where the metamorphosis to effective communication occurs. The chrysalis is that in-between stage that allows the caterpillar to change and transform into a butterfly.

<p style="text-align:center">"And if I decide to become a butterfly,"
said Yellow [the caterpillar] hesitantly. "What do I do?"</p>

<p style="text-align:center">"Watch me. I'm making a cocoon.
It looks like I'm hiding, I know,
but a cocoon is no escape.
It's an in-between house where
the change takes place.
It's a big step since you can
never return to caterpillar life.
During the change, it will seem
to you or anyone who might
peak that nothing is happening—
but the butterfly is already
becoming.
It just takes time." [2]</p>

It Just Takes Time

It takes time is a recurrent theme as the child remains in the chrysalis of silence. It takes time to get the evaluation. Just as there are rights to medication administration,

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[2] Note: From *Hope for the Flowers, by T. Paulis. Paramus, NJ: Paulist Press. Copyright 1972. Used with permission.*

there are rights to finding the correct AAC device for the child; the right method which may or may not be a SGD, the right time, the right child, the right therapist.

Second, it takes time to get payment for the device. Funding for equipment has always been one of the greatest barriers to the successful implementation of communication technology (McDonald, Harris, Price, & Jolleff, 2007; Sevcik & Romski, 1999). In my pilot study (Crisp, unpublished pilot study), one mother reported that it had taken 2 years to get her son's device, and then payment was only secured when a political official intervened. School systems are required to provide this type of technology to students, but that does not always happen, or if it does, it does not happen in a timely manner. Public assistance will purchase the device, but only if there are no other payer sources. Kathy, mother of Brandy, stated that it took 10 years to get Brandy's first device because the school was reluctant to purchase the equipment as the evaluation team was uncertain about Brandy's abilities to use the SGD. Children experience many developmental milestones during their childhood and early adolescent years including those involving the development of language. Because little is known about language development in children that require a SGD who receive their device in a timely manner, there is no way of knowing how much development was impeded in this child because she had no way to express herself for such a long period of time.

Third, it takes time to get the therapy needed to learn to use the device. Parents reported that it has taken months to years to get in with an AAC specialist. Nan tells that she learned of an AAC specialist in her area about 3 years before she was able to secure the specialist's services for Kyle. One mother in the pilot study reported that she had been

working without an AAC specialist for 15 years, and what she had learned about her son and devices had been trial and error (Crisp, unpublished pilot study).

Once the right device is finally obtained, it takes time for the parent to learn to program the device. This is one of the reported reasons for high rates of abandonment of SGD among the children who require them. These devices require a high degree of commitment on the part of the primary caregiver. SGDs have very high support needs, so simply providing the device is not a guarantee that it can and will be used by the family (McConachie & Pennington, 1997; McDonald et al., 2007; Verza, Carvalho, Battaglia, & Uccelli, 2006). Programming can take minutes to hours depending on the subject being programmed and the user's familiarity with the equipment.

Another concern is that it takes time to get everyone on board to use the device. Involving the SGD in the everyday activities of the child and family is not an easy feat. One mother in the pilot study brought her son with her to the interview, but she stated she left the device at home that day because "it was just one more thing to carry." It can be a cumbersome and very tedious process (Angelo, 2000; Angelo, Jones, & Kokoska, 1995; Cress, 2004). As time progresses and the child and family become more familiar with the device, tasks become less time consuming. It is important that all caregivers and communication partners become familiar with the device to increase its usability in a variety of settings and for many different situations such as participation in school.

Furthermore, it takes time for the child to speak using the device. The child who uses a SGD does not have the same inherent knowledge of speech that would occur in a typically developing child, because the child using the SGD does not have peers who are learning language in the same way. There is a great chasm in our understanding of how

the child who requires assistive technology gains speech (Beukelman & Mirenda, 1998). Children who have significant language impairments may continue to use a combination of prelinguistic and linguistic skills for communication. It may take them longer to learn language because of the time that is taken to find the correct equipment and the appropriate instruction in the use of the device.

Finally, it takes time for the device to become one with the child and not just a piece of equipment. Heidegger's notion of "technology is by no means anything technical" (Heidegger, 1977a, p. 4) is apparent as the child learns to use the SGD. To the child, the SGD becomes an extremity, a vital part of life. Kathy describes how the device has become an appendage for her daughter, Amanda.

> Oh, it's always there. It is always with us like an arm and a leg.
> Someone has to grab the device and it is usually me. I have her on one
> arm and her device on the other and I feel very empty without both or
> either. It is always there…

This story also helps to demonstrate how unready-to-hand speech is for children who require the use of a SGD. A family member must always make sure the device is where it needs to be when Amanda needs to use it. It is an extremity, but a detachable one: one that requires thinking and planning to ensure that it is always where it needs to be. When there is no one to help the child with the device or the person helping with the device is not familiar with the device or a lack of understanding about the device, breakdown occurs.

The Breakdown

Much of the breakdown occurs because professionals working with the child and family lack openness. "The possibilities that you are depend on how open you are." (Hyde 2009). Dasein is thought of as engaged openness (Diekelman, 2009). We as

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humans tend to be constituently open and full of possibilities. This allows us to look at the world and see what is and could be, not what is not possible. The professionals that act as support people may include speech language pathologists (SLPs), educators, occupational therapists, and/or medical professionals. Sometimes these support people become at home with a particular device or a specific company's devices and are afraid to step away from that comfortable place to find the right device for the child.

When educators and SLPs performing AAC evaluations are not open to seeing the possibilities that can be brought about by the use of a SGD, then the evaluation can be a very negative thing. Marsha describes her frustrations with Beth's early AAC assessments.

> So I talked to her early childhood teacher about using a device, and she not in so many words, basically said, she can't, she's not capable of that, and the reason for that is that we had known for a long time, is that she had no response to line drawn pictures, she would only respond to photographs…So I think that was the theory behind her speech therapists thinking….

Marsha's daughter, Beth, soon surpassed the expectations or lack of expectations identified by her teachers and therapists. No one told Beth that she could not use this simple device. Beth just did it and flourished. She now has a device that is more appropriate for her capabilities but not without first having to show the people who made the purchasing decisions that she was able to use a more sophisticated device. Once Beth received the more sophisticated device, the ability to communicate became more ready to hand, even though the device remained unready to hand. Once Beth's device was programmed for her, she was able to use it to communicate more effectively. The device became an ingrained part of her daily life and lay await in the standing reserve.

Standing Reserve

"Everywhere everything is ordered to stand by, to be immediately at hand, indeed to stand there just so that it may be on call for a further ordering. Whatever is ordered about in this way has its own standing. We call it the standing reserve" (Heidegger, 1977a, p. 17). Technology has become such an ingrained part of human existence that it is always standing by in readiness for use. While the technology becomes ingrained in the life of the child and family, it may not always be standing in reserve, ready to use.

The child who uses a SGD needs someone to program the device, assist with the use of the device, and sometimes even hand him/her the device. The child also needs to be engaged with people who speak in order to get the assistance needed to use the SGD. We who are speaking live in a ready-to-hand world of technology, so the understanding is very different. Computers, IPODs, cell phones, and Blackberries are all types of augmentative devices that are used by the masses. Many persons would be unable to function in life without these devices which have become such an extension of themselves. This also holds true for the child who uses a SGD. Most people are able to choose when, where, and why, he/she wished to employ the use of which device. For the child with significant physical disabilities who requires a SGD, the device must often be handed to them and set up by another before the child can use it. This makes it no less an extension of the child. Nan describes a situation where the Kyle's device was made unready-to-hand as a form of punishment.

> He was getting speech therapy, and he was there in a self-contained
> Reading group to help with Kyle's literacy skills… Kyle had an aide,
> and she happened to be someone I knew from the community, who
> had an older son with Down syndrome, and I took Kyle to school and
> she said "I'm just going to tell you, I'm sure Kyle will let you know"
> which she knew Kyle was capable of. She said that Kyle was trying to

use his talker to talk in math class and she took it away from him, and
he got mad, and tried to bat at her, so she said "I told him, I was going
to take it away from him for the rest of math class, and I did."

This example of how not to punish a child with a SGD is reminiscent of some of the early

methods of punishment for typically developing students who misbehaved or spoke out

of turn in the classroom. Many of us grew up in an era in which unruly students were tied

to their desks tape over their mouths. This is no longer an accepted educational practice

as it borders on abuse. How then, does it become acceptable to take away a child's

method of speaking?

Taking the device away from the child as a form of punishment should never be

permitted. This story helps to demonstrate the need for more and better trained

professionals to assist children who use SGDs and their families. Currently, there are too

few trained therapists, teachers, and other professionals available to help the parents

make sure that their child has everything programmed into the SGD to communicate

effectively. The story below describes how excited a young teenage girl became when

new things were programmed into her device and she was allowed to express even more

how she was feeling. It also helps to describe how important the SGD became in the lives

of this family.

There was one other time that it was really very emotional for me.
I was excited because she was excited. When we got the Freestyle, when
I told her it was time to go to bed, she would try to pick up the device and
hand it to me, as if to say, hold on to it while I'm sleeping and you better
get to work and make me more words. When she got up in the morning, it
would be sitting on the cabinet ready for her use…
She has came (sic) to think of her communication device as an
extremity…she is a two-ton elephant if you try to leave her device behind
or if she has something to say and hasn't had the time or the ability to
express herself… it took me probably 10 boards before I could create a
board that she could actually say "I love you"… I added the "I love you
button" and she found it and just kept hitting it over and over and over and

that's what really made me cry—when she could finally say "I love you" and she chose to say it, you know. … the thing that is the hardest is that it is she and I against the world in fighting to get her a voice and critical thinking skills…

Kathy is not alone in her frustrations with the lack of support that she perceives from the professionals working with her and her daughter. It is not uncommon for educators to be less than receptive to the needs of a child who uses a SGD. This story also demonstrates how important that continuing to update the device to the needs of the child can be. Busy classes with multiple children requiring different methods of AAC may not be conducive for the educator to learn about every device that is being used. That is not to say that all school situations and educational professionals are in this same position of being unfamiliar or unprepared to use the SGD in the classroom. Other families described professionals and school systems in which things were going very well and, and, they are considered to be doing it right.

Doing it Right

Doing it right describes those stories that tell of professionals and systems that are working together to help the child learn to use the device effectively in a variety of situations that may or may not directly be related to what is considered to be a traditional classroom. Kyle is out of school but continues to participate in a number of therapies and outside activities in his large Midwestern neighborhood.

He pretty much uses the speech generating device for when his other methods of communication are inefficient. He has speech therapy and he does that out at the mall with the speech therapist and uses the SGD and makes Kyle use it out in the community. She takes him out to different settings to help him get more familiar with using the device out in places he isn't familiar with. She does that, and it is very effective.

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This therapist goes out of her way to find the environment that will help Kyle to be most receptive to using the device. According to his mother, Kyle is a very shy young man who loves to be out in the community, but he lacks the confidence to engage people in conversation with his device. By taking him out in the community and allowing Kyle to have successes in his use of the device in this setting, the therapist is helping Kyle become more confident, so he will become more willing to speak out in the community.

It is not only individual therapists who are doing it well. One school that is making an effort to do it right is a school in Pennsylvania which provides services for children with autism. Samuel, age 11 years, has autism. He attends this special school and uses his SGD routinely. According to his mother, Ellen, Samuel tried a number of AAC methods before successfully becoming a SGD user. The school that Samuel attends primarily uses the Picture Exchange Communication System (PECS) to teach the students to communicate. This system involves devising a book of picture cards to hand to a communication partner, to request or communicate something. However, the school is not wedded to using only PECS and is open to other AAC methods. Samuel was the first child to have a SGD, and the school is very supportive and tries to incorporate the use of the Samuel's SGD into most activities. Samuel's mother describes how the school has changed attitudes and gained openness regarding the use of the SGD.

> …there are actually a lot of kids in the school using these speech generating devices. Initially his school was developed using the PECS system, and that is all they ever wanted to focus on was PECS. When the school started enrolling kids who were coming in with these devices, the school had to change the attitude about communication and subsequently did….I would say the children I have seen with communication devices, there are three at this time. There is a fourth one that I have been talking to that is undecided at this time, so we are probably going to end up with four before the end of the school year.

This school is specifically for children with autism and has a classroom size of fewer than 20 students per class in approximately 6 sections. They started with only one child who uses a SGD and are now up to four students using the device and are considering evaluating other children for devices as well. The school is open to helping the child learn using the method of AAC that is the best one for the child, rather than trying to mold the child to fit the use of AAC. Ideally, a class with all SGD users would provide the best opportunities for learning. Some schools are now piloting classes that contain only children who use SGD.

For example, in his book *Schuyler's Monster*, Rummel-Hudson (2008), describes another school that is doing it well. They are actually piloting a class just for the areas SGD users. This particular class is one of several across the nation that allows children who use SGDs to interact with other children who use SGDs in a controlled setting in which interventions can help guide the children in their efforts to become more effective communicators. All of these efforts are to help the child learn to become more engaged in the world community and not just a part of the community of school and family.

Once the child and family learn to use the device in all aspects of their daily life and the child has become a more effective communicator, they emerge from the chrysalis of silence and enter a new world that is full of possibilities. They are ready to become involved in the rhetoric involved in everyday life. Rhetoric is that part of language that when heard challenges the listener to do something (Hyde, 2009). It provides for the give and take of conversation that allows us to grab the attention of the person with whom we are conversing and communicate with them and educate them about what it is that we wish them to know. Once the child is ready to become a part of the rhetoric of everyday

life, that give and take in language where we all can communicate, the child is ready to

emerge from the chrysalis as a new being.

Emergings: The Metamorphosis

She's a butterfly, pretty as the crimson sky
Nothings ever gonna bring her down
And everywhere she goes
Everybody knows she's so glad to be alive
She's a butterfly

Let the purest light in a darkened world
So much hope inside a lovely girl
You should see her fly, it's almost magical
It makes you want to cry, she's so beautiful
(Rich & Aphin, 2003)

The child who learns to use a SGD, like the girl in the song, has so much hope

inside as they learn to fly and become more independent. The child who becomes skilled

in the use of his/her SGD, sometimes even surprises his/her parents by what they express.

Madisen, age 15 years, was very slow to find a device that worked well for her, but when

she did, Madisen began communicating very effectively. To enable her to have more time

to adapt to using the new device at school, Madisen's mother, Wendy, and the teachers

agreed that Madisen should be in a special education classroom for the added support.

Imagine Wendy's surprise when the following happened:

> She {Madisen} made the comment to me, not long ago, maybe three weeks
> ago, *that she would rather be a sponge than speak.* And that almost made
> me cry, because here she is developing some decent access, even if it is on a
> limited basis, but she would rather be in a classroom without a voice to be
> able to learn, because she knows that her years of tapping the educational
> system are limited.

Madisen used her device to express displeasure with the changes in her classes

that occurred because of her need to learn to use the device. Wendy tells how she and her

husband grappled with the decision to move Wendy from a mainstream class where she

was just a silent observer into a class where there would be more assistance for Madisen to use her device. Madisen was not able to express her opinion at that point, but once she was, Madisen indicated her displeasure about being removed from a rich environment to one that was more task oriented. As Madisen learned to communicate more effectively, she also began expressing her ideas and opinions about other things.

> And when they were getting ready to send her a loaner device from Dynavox and asked what color she wanted because they thought she might like the pink, and I asked her, and she said "No, because it might clash with some of my outfits" It's really kind of funny because she ended up with silver, and she has been using silver.

This type of remark about a specific color of device clashing with her outfits is one that might be expected from a typical teenager, but without proficiency with the use of her device, Madisen would never have been able to explain why she did not like the pink one. Madisen expressed things that were important to her that would have remained unrevealed without the device. She began blossoming much like any other typically developing teenager. Madisen is no longer silent and thoughtful; she is verbose and engaging even if it takes her a while to find the appropriate words. It may not always be easy, but Madisen now has a way to express her thoughts and ideas. She is a typical teenager in every way and has the capability of language befitting a teenager.

This story also demonstrates how important it is that the devices have age appropriate language on them as well. Teenagers should not be limited to a primary vocabulary or a toddler vocabulary just because nothing else is available. It is important to make sure that the person programming the device allows for this type of self-expression as well as the social-niceties. Wendy describes how she and her husband have

tried to program Madisen's device so that she is able to express herself in a manner

similar to a typically developing teen.

> …so one of the phrases on the talk page is "What the _____"
> (Madisen's mom was laughing as she said this but she did not
> fill in the blank as to the exact phrase) and that has become one of her
> favorite things, and I will say Madisen, we do not say that in this house,
> and she just begins laughing. She wants to go to it, and it's a really hard
> place to get {to}, so it's funny to me. I'm actually wanting her to improve.

Madisen's use of the phrase "What the _____?" demonstrates how she has

changed from being a quiet, happy little caterpillar into a typical teenager who has

thoughts, feelings, and ideas that are important and need to be acknowledged just the

same as thoughts, feelings, and ideas expressed by any other teenager. She is able to

challenge and test her limits in a way that was never possible before. Her parents are

allowing her to have the freedom to test her limits by acknowledging that Madisen needs

to have the same language as her typically developing peers.

Acknowledgement

Heidegger (1977a, p. 237) writes that "Every affirmation consists in

acknowledgement." Acknowledgement opens up a place where things can happen.

It helps us move from the realm of seeing into the realm of observing and appreciating

the crafts and talents of others. Positive acknowledgement helps people feel good about

what they are doing. The affirmation of doing something well is a strong motivator and

helps to encourage the trial of new things.

Madisen's story is so illustrative because she resisted communication for so long.

Early attempts to find a communication device were met with opposition because it was

easier to let someone else to speak for her. But when the right person came to do the

evaluation, and Madisen was really acknowledged, it was like a light turned on, and

Madisen realized there was a better way for her to share herself with others.

> Madisen was sure she wanted a Tango, she wanted a Tango, absolutely sure, she wanted a Tango, because it just had the WOW factor because it has a digital camera as part of it, but when she got it in front of her, it took a few minutes and she was like "Forget this nonsense". It was socool to see her say I really thought that is what I wanted, but it ain't even close.
> She [the SLP] brought a Mercury out with her also and it is Dynamically pro and it was a whole lot closer to what Madisen wanted so Nancy said, "let me come back with the Dynavox rep {sic} when she's coming out". And they came out, and I just walked away for a little while, and they were just flabbergasted with how quickly she got into those areas. And to see over a period of about three weeks this was, to see four individuals who didn't know my child be amazed with what she could do after they had already decided what she could do…
> They started talking to her differently. They started not talking to her with a baby voice. They started asking her what do you think about this. It was like, she emerged on the other side of those three weeks she emerged on the other side of a young lady as she, like she could control the process, and that was an enormous growth for her to see her from everything from that and then deciding she wanted a silver device to go. It was like all of a sudden she took charge, and whether it was the device knowing that people responded to her differently when they saw her empowered, that it changed how she interactedwith everyone.

The acknowledgement demonstrated by the two representatives who were helping

Madisen choose the best device for her substantiates how important acknowledgement or

authenticity is to the life of any person. It does not matter so much who provides the

acknowledgement, just that the person be acknowledged.

> We are creatures whose well-being requires acknowledgement from those who would have us return the favor. Indeed, we are social beings—born from others and, right from the start, in need of family, friends, and even strangers who are willing to open themselves to and acknowledge our presence, be it joyful or desperate.
> (Hyde, 2006, p. 119)

However, acknowledgment might not always be positive. Some forms of

acknowledgement can be negative and hurtful. Kaley tells of how her son Liam, 8 years,

has autism. The battle to find effective communication for him has been very taxing. Children with autism always have some kind of communication disorder, and many are unable to speak even though they are able to make noises. Liam does not have the ability to speak words, but he uses sounds and gestures to express his ideas when his SGD is not available. Some of the sounds that he makes are similar to sounds made by animals. At times, people in the community have been rude and not very nice when Liam made the noises and would ask things like "where's the horse." These incidents have been very painful to Kaley who teaches English to persons from other countries and demonstrate how negative some forms of acknowledgement can be, especially when rhetoric and communication are very important to her. Kaley has advocated finding a way for Liam to communicate so that he receives positive acknowledgement instead of negative. Now that he has his SGD Liam is even able to order his favorite meal.

> Liam loves to eat pancakes, and he loves to drink lemonade. We try to do activities for language and sentence structure with things that he loves when we go out for things like that, so we make him order his own breakfast and he mastered that for several months, and people got a big kick out of it. And one of those times he put in independently at the restaurant "I want pancakes" and she asked him what to drink, and hesaid "I want lemonade" and I looked at my husband because that moment in time, the visual contact was with Liam. There was no looking at my husband or I. For in that moment, the waitress had contacted with Liam, a 7-year-old, and she listened, and smiled and said "thank you," and I get all emotional just thinking about it.

This story helps to describe how important acknowledgement can be, especially to a child who seldom receives acknowledgement from persons who do know him/her well. Acknowledgement is shown in all kinds of ways, in all kinds of forms. Sometimes as Heidegger (1971b, p. 7) states, it is "the splendor of the simple" found in phenomenology that allows us to recognize acknowledgement. Monica tells of a visit to the museum with

her daughter Beth when the acknowledgement came from a small child, a stranger, but the resonance of the child's acknowledgement is almost deafening.

> She was at the children's museum…One of the things that she really likes are these peg flowers, that you can plant in a fake little garden. She would always go there….a little girl who was younger than Beth came up, and I can't remember what she said to begin with, but she said something like"oh, you like the flowers, I like the flowers too." And then the little girl picked on up and started to smell it, and Beth hit the button to say "these flowers smell good."And I was like, trying to not be there, you know. And the little girl, she was maybe three years old. She didn't react at all, other than "yeah, they do." She just responded to what Beth said. She didn't ask about the device. And Beth doesn't even normally look at people out in the world because she doesn't expect them to respond to anything,any signs or anything. She expects them to talk to me, which is somewhat demoralizing,but she, this little girl. I don't know if she had experience with something like this before or what.
> So they kind of went through, and she asked me "what's her name?" and I thought "oh no, Beth doesn't know where to find that button yet" I had it on there, but this was just a rental and didn't know where that is, so I just kind of quietly interjected "Beth" while silently crossing my fingers that she wouldn't turn back to me and start talking through me. Well she just kept looking at Beth and said "Oh Beth, I have never heard that name before, my name is Dana, let's do this". And they just played, and then somebody called the little girl…That is my dream for her, that that is how people will react to her. She wasn't even reacting to the device, she was reacting to Beth. I don't know if this little girl had even noticed that the voice was coming from the box. She didn't even look at it. I mean, that is just the story that I wish we could replicate.

This little girl was open and engaging without even thinking about it. It was inherent to her. She did not care that the voice was different or that it was coming from a box. She just wanted to play and share with a new friend. We also see Heidegger's concept of the concealed being revealed. Technology is a way of revealing (Heidegger, 1977a, p. 11). Just as the caterpillar goes into the chrysalis to transform into a butterfly, the child with a SGD goes from a life of silence to a future of possibilities while learning to use the SGD. Children who have gone along day after day in a world of silence (the routine) suddenly become more than a part of the room, an interactive component, once

they have the SGD. The essence of the child's open engagement becomes readily apparent as he/she becomes more adept at communicating his/her thought, ideas, dreams, and wishes to those around them. Acknowledgement can help the child let go of his/her old fears about participating in communication until one day, the child becomes a social butterfly. This is described in this scene from Hope for the Flowers in which Yellow, the butterfly, tries to coax her friend Strip, who is still a caterpillar, to enter the chrysalis.

They came to a
branch from which
hung two torn sacks.
The creature kept on
inserting her tail,
into one of them.
Then she would fly to him and touch him.

Her feelers quivered
and Stripe knew she was speaking.
He couldn't make out the words.
Then slowly he seemed to understand…
Somehow what to do.
Stripe climbed again.
It got darker and darker
and he was afraid
He felt he had to let go of everything.
And yellow waited
Until one day…..[3]

The story of the butterflies told by Paulus is unfinished, much as the world of the child who uses a SGD is unfinished. The process of metamorphosis for the child who uses a SGD and his/her family is never-ending. We, as humans are always becoming; the future is always full of possibilities if we remain open to them. As the child moves out of a world of silence and into a world of possibilities, it becomes likely that the child will

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[3] Notes: From *Hope for the Flowers, by T. Paulis. Paramus, NJ: Paulist Press. Used with permission.*

become part of the rhetoric that is essential to humans, that give and take in conversation that allows us to communicate and educate the others with whom we converse.

Review of the Pertinent Literature

Metamorphosis has long been a description for change. From Kafka's (1915) novel in which the metamorphosis was unpleasant when the primary character turned into an insect overnight to current stories of inspiration written by women with alopecia (Crittendon, 2008), metamorphosis describes dramatic changes in appearance, abilities, circumstances, and/or character. Metamorphosis occurs quite naturally in the wild: a caterpillar transforming into a beautiful butterfly or a tadpole growing and changing into a frog both demonstrate how rapid and dramatic these changes can occur. The lifecycle of a butterfly begins when the egg is laid on the underneath side of the leaf. After a few days, the egg hatches and the caterpillar emerges and begins its work of eating. After the caterpillar has grown to its adult size, it again attaches to a leaf and forms a chrysalis, in which the work of transforming into a butterfly takes place. There is a chemical breakdown of the caterpillar which allows for the formation of the head, wings, antennae, and legs of the butterfly. Once the butterfly is formed, it emerges all wet and limp. In about 2 hours, the wings are dry and the butterfly is ready to take flight.

In her 2003 study, Stiffler discusses the metamorphosis experienced by mothers and their adolescent daughters during the extreme and rapid changes encountered by mothers and daughters during this tempestuous time of the daughter's life. As with the caterpillar's transformation into a butterfly, the process is not always easy or pretty but, in most cases, the mother and daughter emerge on the other side stronger and more intertwined as a result of the struggles to achieve this metamorphosis.

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The Happy Caterpillar

Infants emerge from the womb into a world where language surrounds them. Everyone wants to engage the child in an effort to elicit the first coo or smile. Communication and social development are interwoven during the first few months of life (Landa, 2007; Vygotsky, 1978, 1989). For the preterm infant or a child with a disability language, development may be delayed slightly or significantly (Abbeduto, Brady, & Kover, 2007; Abbeduto, Warren, & Conners, 2007; Landa, 2007; Marston, Peacock, Calvert, Greenough, & Marlow, 2007). It is not uncommon for children with significant disabilities to remain in the prelinguistic stage if the disability has robbed them of speech. It is important for parents and providers to take advantage of this early developmental period of language even if the child is never able to speak (Romsky & Sevcik, 2005). This will help the child to have a firm foundation for language even if he/she is not able to speak. This foundation will be helpful when the child is ready for an AAC evaluation to determine the appropriate method of assistance needed.

As the child progresses through this early stage of language development and discovers that he/she is not able to communicate effectively with others in his/her world, frustration may set in (Goldbart & Marshall, 2004; Marshall & Goldbart, 2008). The child wants to communicate with those in the immediate environment. The inability to do so may lead to physical aggression, tantrums, or other undesirable behaviors. The child realizes that "he/she wants more" and so does the family.

Alant and Lloyd (2006) write "That a person communicates is, therefore, much more important than how a person communicates. The ability to understand others and to express oneself; thus to participate in creative development of meaning with others, is at

the basis of human interaction" (p. 141). Open engagement is ready-to-hand to people capable of speech. Children who are unable to speak may attempt to find another way to convey their wants and wishes. Multimodal communication methods may be employed to assist the child. Some of these methods include gestures, vocalizations, sign, expressions, as well as pictures, symbols, or AAC (Loncke, Campbell, England, & Haley, 2006; McNaughton et al., 2008; Wilkinson & Hennig, 2007).

Family members and others who are in tune with the child are often able to act as an interpreter for gestures, sounds, and expressions. However, most people in the general population will not be able to recognize what the child is trying to convey, leading to more upset and frustration for the child and family. As attempts to communicate become less successful and the frustrations of being unable to communicate escalate, the child and family are more than ready to begin the search for a method to enable the child to become a more effective communicator.

The Chrysalis of Silence

It becomes imperative to provide children who have complex communication needs with access to all aspects of communication as early as possible to prevent increased developmental issues related to the communication delay or disability (Light & Drager, 2002). It has often been said "the earlier the intervention, the greater the outcome." This holds true with children who are learning to use a SGD. The best time to learn to use a device is that period of time in which language learning is at its greatest. Children are able to learn language later, but it make take them more time to achieve the same successes with the device if the SGD is introduced in later childhood or adolescence.

It is important to remember that learning to use a SGD will not happen overnight. It takes time. In his book, *Schuyler's Monster,* Rummel-Hudson (2008) describes taking his daughter to a child development center and paying hundreds of dollars out of pocket for an evaluation that had one sentence about Schuyler's inability to speak. This evaluation which yielded such little information about Schuyler's communication disorder occurred while the family physician was still trying to get the family an appointment with the Yale Child Study Center and demonstrates that not every evaluation provides the information needed to assist the child in obtaining a SGD. This encounter did nothing to promote Schuyler's use of a SGD. Previous trials with PECS had bored Schuyler, so most of her attempts to communicate were via sign or gesture. It was not until later when the family moved to Texas that Schuyler received the AAC evaluation that provided her SGD, but it was during a couple of years when important language development time had been lost. It is important to remember that all of these steps take time.

It takes time to find the appropriate method of AAC for the child. It is not a one-size-fits-all type of equipment. Each method or multiple methods of AAC must be individualized to the child to achieve the greatest efficacy in use of the methods. In my pilot study (Crisp, unpublished pilot study), one mother told of her battle to obtain her child's device. It took 2 years and the intervention of a senator before the device was purchased, and by that time, the child had outgrown many of the features of the present device and was ready to move to a more complicated device.

It sometimes takes time to obtain the appropriate funding to purchase the device. Parents report that many insurance companies pay only $1,500 per year toward the

purchase of a device that may cost upward of $20,000 depending on the degree of technology needed. Children who require eye-gaze technology or other special technology require the most expensive device to insure that their communication needs are met. Other studies also report that funding has been and continues to be one of the greatest barriers in achieving effective communication modalities for persons who are unable to speak (Crisp, unpublished pilot study; McDonald et al. 2007; McNaughton et al., 2008: Sevcik & Romsky, 1999). In my own experience with my daughter's first device, the insurance provider agreed that she qualified for the use of a device, but they did not want to pay the amount of money requested by the vendor. It took the intervention of the Indiana Protection and Advocacy Commission to work out a deal between the insurance provider and the vendor to insure that my child got her device

The battle for the family does not end when the device is obtainedas one of the most difficult and time consuming tasks for the family is learning to program and support the device for the child to be able to use it effectively. One 2006 study reports that families considered some of the greatest barriers to using their child's AAC device as the time needed to program the device and the lack of supports available to help the families learn to use the device (Bailey et al., 2006). Marshall and Goldbart (2008) found that the majority of families in their studies reported that the roles and responsibilities of the primary caregiver had increased since the child had received the device. This was due in part to the time it took to insure that the device was ready-to-hand for the child at any time.

In another study, Binger and Light (2006) surveyed early intervention speech language pathologists about the demographics of preschoolers using AAC in

Pennsylvania. They found that 12% of all preschoolers in the districts surveyed required some type of AAC. One of key points arising from the study was that SLPs did not have the appropriate knowledge and training to support communication across all modes of communication, and that few SGDs were utilized, possibly due to lack of knowledge and experience using high tech communication systems. The findings of this study support the concerns that the families have about having inadequately trained supports to help the family learn to use the device adequately.

A third study (McNaughton et al., 2007) cites barriers such as a lack of trained professionals both with SLPs and within the school system as inhibiting the use of AAC. Struggles with the school system, identified as a lack of knowledge and interest were very frustrating to parents. In my pilot study, one mother, a former teacher, shared that she was now providing homeschooling for her child because the school was very unsupportive in her child's use of a SGD.

Multiple other studies describe other breakdown areas including the lack of supports available to assist families in the ongoing use of the device (Bailey et al., 2006; Goldbart & Marshall, 2004; Marshall & Goldbart, 2008; McNaughton et al., 2008). Technical breakdowns were highlighted as one of the greatest problems in the area of support. Parents are often responsible for the costs associated with renting a device when the child's device has to go in for repair. There are few lending entities available and when they are, the device may only be available for part of the time that the child's device is being repaired.

Conversely, there are places that are providing wonderful resources for families. Rummel-Hudson (2008) describes the SGD classroom that Schuyler is attending and

discusses all of the positives of having his daughter in a classroom with children who are truly her peers in every way. Other school systems in other parts of the country also have SGD classrooms. This allows for the children to communicate with their peers in the same way. It fosters and promotes using the device in all aspects of the child's everyday life.

Such promotion occurs in SGD camps, SGD play groups, and adult classes for persons with disabilities which are available in a number of cities across the United States. These types of activities encourage the child to become more comfortable in communicating in all types of settings. Nancy describes an incident at camp where her shy son told a joke to everyone at the camp and how he responded to the positive acknowledgement that he received from his peers, the counselors, and other parents.

> Activities and camp for families… it's a parent child camp, so You would go with your kid and its run by the speech therapist and they have volunteer speech therapists, and everybody there is really, really, adept at the augmentative communication. And so the idea is,that whatever device you have, you come and you do regular camping activities but you have a device to communicate…they wantall the kids to be able to share, and that is gonnabe like Benjamin's hardest thing since he is so shy, but what is funny though is that he, Benjamin got around children using these devices, he isn't around other kids with devices so he didn't have any role models.
> He went to this camp…and I can't tell you how motivating that is. He started using the device more and more…I would see thatwhen they would ask if anybody had anything to share, he would raise his hand. You know, not all the way up because he can't lift his arm up that much, but he wanted to participate. That's fabulous and he wantedto tell this joke…And he told this joke…And people clapped. He got through it and people clapped, and I got this fabulous picture, I just caught at the right time, of huge big grins on his face, and so proud of himself and so thrilled that everyone else is clapping. To me that is the perfect story about using the device, about participating with others, showing people what you know what you like.

This kind of acknowledgement is important to everyone. Benjamin lit up when he received acknowledgement for telling a joke. Positive acknowledgement is encouraging,

nurturing, and can even be considered life-giving (Hyde, 2006). It makes us feel good

about ourselves and the person who acknowledges us. Positive acknowledgement also

recognizes the importance of the individual as well as the action that is being performed.

"Acknowledgement is a conscious act of creation that marks an origin or beginning, and

opening to space-time where people can feel at home as they dwell, deliberate, and know

together" (Hyde, p. 10). According to Heidegger, acknowledgement allows us to move

from a world of seeing to a world of observing. He further goes on to discuss the

presence of acknowledgement:

> Man obviously is a being. As such he belongs to the totality of being—just
> like the stone, the tree, or the eagle. To "belong"here still means to be in
> the order of Being. But man's distinctive feature lies in that, that he, as
> being who thinks, is open to Being, face to face with Being; thus man
> remains referred to Being and so answers to it. Man is essentially this
> relationship of responding to Being.   (Heidegger, 1969, p. 31)

By responding to man with open engagement, we are actively responding to both

Being and being. This acknowledgement provides us with a place where we are able to

listen and respond to the "call of conscious," that voice in your head that you hear when

things breakdown. It is a call that summons us, especially in moments of personal crisis,

to assume ethical responsibility of affirming our freedom through resolute choice (Hyde,

2009)

Summary

The most significant finding revealed in this study was the metamorphosis of the

child and family as the child learned to use the SGD and communicate more effectively

with the general public. This metamorphosis consisted of three main themes: the happy

caterpillar, the chrysalis of silence, and emergings: the metamorphosis. These categories

describe the dramatic changes that occur both to the child and the family as the child

becomes a SGD user. The process is not smooth and without detours, but the process continues in spite of the detours and the child and family emerge on the other side to a world of possibilities that would not have been available if the child had not learned to use the SGD.

Subthemes arose in each of the three main themes. The child began the process of changing from a happy caterpillar into a chrysalis when the child and/or desired to communicate more effectively. Children and families want more. They want to be an active, engaging part of the discourse surrounding them. It is not merely enough to stand on the side lines and listen to everyone else without ever being able to be heard. Parents who know that their child is capable of being more than a silent sponge push to find or devise a method or methods that can be used to help the child to communicate more effectively. The receipt of the device is only a beginning to the possibilities awaiting.

Once the child receives the SGD, he/she and the family move into the chrysalis of silence where the dramatic changes needed for the child to learn to be an effective communicator take place. It just takes time to get things done. The process can take months or even years, but the child and family will get through the changes and emerge on the other side if given the appropriate training and support along the way. The parents have to be open enough to work through the breakdown and emerge on the other side. The child and family need to work together to insure that the device is always ready-to-hand so that the child can actively engage in conversation with others in their environment. SGDs should be considered no less a part of everyday life than IPODS, cell phones, and Blackberries. The technology used for communication should always be ready-to-hand and ready for use.

As the child becomes a more effective communicator, the child and family complete the metamorphosis, emerging on the other side as a whole new being, one who can openly engage in the rhetoric of the world around them. The child can be seen as an individual with thoughts, ideas, talent, and a sense of humor and be acknowledged as such. The child and family enter a world of possibilities where the simple matter of being unable to speak in no way interferes with the child's ability to communicate and participate in the rhetoric that surrounds us.

CHAPTER FIVE

Discussion and Implications

Discussion

In this section, we will briefly discuss the specific aims and the results of the data analysis, as well as the hermeneutic process, implications for future nursing practice and education, and the limitations of the study.

Revisiting the Specific Aims

The results of the data analysis provided insight on both intended aims of the study: however, more time was devoted to the actual life experience of Aim 1 than the costs identified in Aim 2. The primary caregivers were open and happy to discuss all aspects of life with their child as the metamorphosis occurred.

Aim 1: Describe the experience of families who have a child who is currently using or has previously used a SGD as viewed through the lens of the child's primary caregiver. Each mother addressed both positive and negative experiences related to the use of the SGD, with most of the negative experiences being related to the lack of appropriate supports to assist the child and family to be successful. All of the mothers described the metamorphosis that occurred as her child learned to be a more effective communicator using the SGD. This description of experiences has helped to illuminate what life is like for the family when the child is learning to use a SGD.

Aim 2: Explore in greater detail the preliminary findings from the pilot study regarding financial, emotional, developmental costs, to the children and families, as well as the lack of appropriately trained professionals and excessive time sequences from evaluation to receipt of the device. Each mother addressed the costs experienced by her

child and family; however, the majority of mothers preferred to talk about the child's metamorphosis rather than the barriers to achieving the metamorphosis. The discussion of "Mom" moments, those moments when the mother felt so much pride and love that she thought her heart would burst, far exceeded the discussion of many of the negative issues investigated in other studies by other researchers. One subject that was mentioned by all of the mothers was the lack of appropriate support personnel to assist them with the use of the SGD. This problem has been identified in previous studies and will continue to be identified until the professionals that families rely on for support receive adequate training in the use of the devices.

The Hermeneutic Process

"Phenomenology as an approach lets us see by helping to uncover what is hidden or concealed" (Johnson, 2000). It is a process that allows things to reveal themselves; a process that allows the researcher to be open to the world. Because nothing in life is ever seen completely, it must be interpreted. An understanding of the hermeneutic process is needed to fully understand the findings of the study.

The goal of the hermeneutic process is to gain an understanding of everyday experiences as they occur in the world by the people who experience them, finding the common threads in meanings, encounters, events, customs, and traditions and exploring them without changing their meaning in anyway. It is a process that has no beginning and no end but is a continuing experience for all persons involved in it. The process is circular. Understanding is made of the whole in reference to all of the parts which are then in turn referenced to the whole. Thus the process is never ending.

Furthermore, meaning is also never ending. It is referenced in time, and the meaning may be different tomorrow than it is today. Meaning is always seated in what we already know both historically and contexturally. Learning to resonate with new experiences allows new meanings and new ways of thinking to come forward (Sloan & Swenson, 2003). Meaning is interpreted by different people in different ways at different times, so it is important to receive input from others to ensure that an individual researcher is not blinded by what he/she already knows.

Implications for Nursing Practice and Education

The implications for practice are not limited to nursing as the implications also hold true for speech language pathologists and educators. These implications include the need for more support for the child and family as they learn to use the SGD, the need for better ways for the child to use the device to discuss pain and feelings, the need for the device to be available whenever and wherever the child needs it, and better training for all persons involved in the use of the device.

Currently few nurses know what a SGD is, let alone how they function due to a lack of exposure to the devices. Assistive technology for persons with disabilities is becoming more prevalent in all community settings, so some type of educational offering should be considered to introduce nursing students to what technology is available and when and where it might be encountered. It is my "call to conscience," or charge, to design a course to help students in multiple disciplines to learn about the types of assistive technology available for people with disabilities and how best to assist people learn to use the devices effectively in their own lives.

Furthermore, nurses are in a position to help hospitalized patients communicate more effectively by advocating that the person who uses a SGD has access to it at all times. Nurses can also help educate vendors on the types of pages that are needed on the devices to help the child to express how he/she is feeling, where he/she hurts, and other responses that can make a clinic visit or hospital stay easier for the child, family, and nursing staff.

Educators and speech language pathologists also need to have more training and greater availability to provide support to children and families who use a SGD. Ideally there would be augmentative communication specialists trained in both the speech language and education arenas so that there is an abundance of trained professionals to aid these children and their families.

Finally, users, family members, nurses, educators, and speech language pathologists need to be more vocal in educating society on what is needed for a SGD to become more ready-to-hand. Vendors need to be open to hearing what else is needed to make the SGD more user-friendly to the largest number of users. Politicians need to be informed about how long it takes to get some of the devices and how little insurance companies are willing to pay for the child's right to speak. It has long been my desire to provide a voice for children with disabilities and their families, and as a recent appointee to the Indiana Governor's Planning Council for Persons with Disabilities, I am now in a position where I can do that. For my interview with the council, I described my work with children who use SGDs and their families and my desire to insure that devices would be available for any child or adult with a disability who needs one. One of the members of the interview committee stated that this was a service that they had not

considered before but will consider it more closely in the future. By sharing my research in all realms, I hope to provide education to a variety of lay persons, officials, SLPs, educators, and families of children who are unable to speak about the importance of ensuring that SGD or some other type of AAC is available for every child and adult who requires communication assistance.

<div align="center">Limitations</div>

One limitation to this study is the homogeneous nature of the participants. All primary caregivers were well-educated, Caucasian women in the mid to upper socio-economic class. All of the mothers had at least some post high school education, even if they did not complete a college degree. All of the mothers were computer literate. All but two who had just received or were awaiting receipt of a new device, were well versed in the programming of their child's particular device. This limitation was due in part to the fact that few lower income families have the financial and technical resources to support the use of a SGD.

A second limitation is that all recruitment was done via the World Wide Web. Participants were recruited using an Internet list-serv to which the researcher belongs, as well as two *e*-newsletters. This limited the population to persons with access to the Internet and one or more of the recruitment sites.

Even with these limitations, mothers from a wide geographic area were interviewed. I spoke with two mothers each from Colorado, Indiana, and Wisconsin. Other mothers were recruited from California, Maine, Pennsylvania, Minnesota, and Louisiana. Mothers ranged in age from mid 30s to early 50s. Ten were birth mothers and

one was an adoptive mother. Children using the SGD ranged in age from 4 to 23 years and had been using the device from 2 months to 18 years.

The study would have been stronger if interviews had been completed with fathers, siblings, and the SGD users themselves. In future studies, I plan to interview all family members to investigate whether various family members view family experiences differently as one would expect because each participant views the experience through his/her own lens. Recruiting family members from other races/ethnic groups, education levels, and socio-economic levels would also strengthen the study.

In spite of the limitations, I believe that the findings of my study will be useful and add to the knowledge base of anyone who works with children and families who use SGDs, and will hopefully be used to educate society about the challenges faced by these children and families in a ready-to-hand world.

Appendix A

Initial Probes and Study Questions

Tell me about what a normal day is like for your family.

How do you use the device in your child's everyday life?

What do your other children think of the SGD?

How has the use of the device affected the development of your child and family?

What would you like other people to know about what it is like to have a child who uses an SGD?

If there was one story you could tell about what the SGD has meant to your child and family what would it be?

Demographics

Race

Gender of the child

Gender of the caregiver

Age of the child

How long has the child been using the device?

Type of device

Number of persons in the family

Number of persons assisting with the device

Educational level of the child

Educational level of the caregiver

Appendix B

Amended Probes and Study Questions

Tell me about when you first found out your child was going to need augmentative communication and how did you get from that point to where you are today.

Tell me what it was like for you and your child when he/she learned a way to communicate more effectively.

What is a typical day like for you and your family and how do you incorporate the device into everyday life?

Who all participates in the use of the device?

What do the other children think?

How would you like to see the device make your child's life better?

What does the device mean to you and your family and how would life be different without it?

Do you have a name for the device?

What would you want to tell other people about what it is like to have a child who uses a SGD?

If there was one story that you could tell the world about what the SGD has meant to your child and family, what would it be?

Demographics

Race

Gender of child/Gender of caregiver

Number of persons in the home

Number of persons participating with the use of the device

How old is the child?

What type of device are they using?/How long has the child been using a device?

What grade is the child in?

Table 1

Types of Assistive and Alternative Communication

Method of AAC	Type of AAC	Technology Level of AAC
Speech/Vocalizations	Unaided	Low Technology
Body Language	Unaided	Low Technology
Sign Language	Unaided	Low Technology
Facial Expression	Unaided	Low Technology
Hand Gestures	Unaided	Low Technology
Pointing	Unaided	Low Technology
Writing	Aided	Low Technology
Morse Code	Aided	Low Technology
Communication Board with		
Alphabet	Aided	Low Technology
Pictures	Aided	Low Technology
Symbols	Aided	Low Technology
Photographs	Aided	Low Technology
PECS	Aided	Low Technology
Computers/SGD		
Keyboard	Aided	High Technology
Touch Screen	Aided	High Technology
Mouth Stick	Aided	High Technology
Eye Gaze	Aided	High Technology
Digitized Speech	Aided	High Technology
Synthesized Speech	Aided	High Technology
Dedicated Communication		
System	Aided	High Technology

Crisp (unpublished manuscript) adapted from DeGennero (2004)

Table 2

Milestones of Early Communication Development

Typical Age	Communication Milestones
2-4 months	cooing and laughing
4-12 months	babbling noises nonbabbling noises understanding of 3-50 words begin vocal turntaking begin making consonant sounds
12-23 months	comprehension of 2-word sentences pointing to body parts production of 10 words begin to name colors begin to put 2 and 3 words together can call family members by name developed vocabulary of up to 300 words
24-35 months	beginning understanding of "w" questions can talk about objects that are out of sight comprehension of 3-word sentences can follow 2- and 3-step commands beginning to produce 3-4 word sentences intelligible about 50% of the time begin to tell recite stories can tell a story from pictures
36-48 months	using 3 word sentences consistently beginning to use descriptive words can follow more complex commands storytelling becomes more intricate speech is 75% intelligible

Luinge, Post, Wit, & Goorhuis-Brauwer (2006)
Paul (2001)
Siegler & Alibali (2005)

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Vygotsky, L. (1989). *Thought and Language.* (A. Kozulin, Trans.). Cambridge,

MA: MIT Press (Original work published 1934).

Vygotsky, L. (1993). *Collected works, Volume 2: The fundamentals of defectology.* New York: Plenum Press.

Vygotsky, L. S. (1978). *Mind in society: The development of higher psychological processes.* (M. Cole, V. John-Steiner, & K. Southerman, Trans.). Cambridge, MA: Harvard University Press.

Walton, R. (2000). Heidegger in the hands on science and technology center: Philosophical reflections on learning in informal settings. *Journal of Technology Education, 12*(1). Retrieved 8/29/07 from http://scholar.lib.vt.edu/ejournals/JTE/v12n1/walton.html

Wang, K-W. K. & Barnard, A. (2004). Technology-dependent children and their families: A review. *Journal of Advanced Nursing, 45*(1), 36-46.

Wilkinson, K. M. & Hennig, S. (2007). The state of research and practice in augmentative and alternative communication for children with developmental/intellectual disabilities. *Mental Retardation Developmental Disabilities Research Review, 13*(1), 58-69.

Williams, M. B. (2006). Myth: There is a perfect device for every person. *Augmentative Communication News, 18*(2), 7.

Windsor, J., Glaze, L. E., & Koga, S. F. (2007). Language acquisition with limited input: Romanian institutions and foster care. *Journal of Speech, Language, and Hearing Research, 50*(5), 1365-1381.

Wolf, C. G. (2007). Talking technology: Your user's guide to assistive communication. *Neurology Now, 3*(4), 40-41.

Wrathall, M. (2005) *How to read Heidegger.* New York: W.W. Norton & Company.

Zeitlin, D. J., Abrams, G. M., & Shah, B.K. (1995). Use of augmentative/alternative

communication in patients with amyotrophic lateral sclerosis. *Journal of*

Neurological Rehabilitation, 9(4), 217-220.

EDUCATION

Place	Degree	Date
Indiana Central University Nursing/Religion (AKA University of Indianapolis) Indianapolis, IN	ASN	1980
Indiana Wesleyan University Nursing Marion, IN	BS	1997
Indiana University School of Nursing Pediatric Clinical Nurse Specialist Indianapolis, IN	MSN	2002
Indiana University Clinical Science Developmental Pediatrics Teaching in Nursing Indianapolis, IN	PhD	2009

ACADEMIC APPOINTMENTS

School/Location	Appointment	Date
Indiana University School of Nursing Indianapolis, IN	Visiting Faculty	2003-2004
Indiana University School of Nursing Indianapolis, IN	Research Associate	2004-2007

CLINICAL APPOINTMENTS AND CONSULTATIONS

Employer/Location	Position	Date
Riley Child Development Center Indianapolis, IN	Clinical Nurse Specialist	2002-2009
Integrity Healthcare Services Indianapolis, IN	Clinical Nurse Specialist Pediatric Infusion (prn)	.2003

Riley Hospital Metabolism and Genetics Indianapolis, IN	Clinical Nurse Specialist	2003-2004
Northpoint Pediatrics Indianapolis, IN	Weekend Triage Nurse	2001-2002
Early Steps Rehab Indianapolis, IN	Pediatric Services Coordinator	1999-2002
Heritage House Children's Center Shelbyville, IN	Nurse Educator	1999
Riley Hospital for Children Indianapolis IN	Staff Nurse Pediatric ICU	2007-2009
Visiting Nurse Service Indianapolis, IN	Pediatric and Rehabilitation Care Coordinator	1995-1997
Lifeline's Children's Rehab Hospital Indianapolis, IN	Weekend Manager Evening Manager Staff Nurse	1993-1995 1988-1993 1987-1988
Heritage House Children's Center Shelbyville, IN	Staff Nurse	1985-1986
Riley Hospital for Children Indianapolis, IN	Staff Nurse Toddler Unit	1984-1985
Heritage House Children's Center Shelbyville, IN	Assistant Director of Nursing Staff Nurse	 1983-1984 1980-1983

CERTIFICATION

PCNS-BC	Pediatric Clinical Nurse Specialist, ANCC	2004-2009 2009-2014
CRRN	ARN Certification Board	1991-2011
CDDN	DDNA Certification Board	2004-2008

PROFESSIONAL ORGANIZATIONS

Association of Rehabilitation Nurses	1990-2008
Pediatric Special Interest Group Co-Chair	1984
Pediatric Special Interest Group Chair	1985
Conference Local Chair	1995
Indiana Association of Rehabilitation Nurses	1990-2005
Positions held: Secretary, Vice-President, President, Ex-Officio President, Conference Chair	
Developmental Disabilities Nurse Association	1993-2009
Indiana Chapter of DDNA	1993-2009
Sigma Theta Tau International, Alpha Chapter	2000-2009
Midwest Nursing Research Society	2002-2009
National Association of Clinical Nurse Specialists	2002-2009
American Speech and Hearing Association	2008-2009
International Society for Augmentative and Alternative Communication	2008-2009

HONORS

Sigma Theta Tau International, Alpha Chapter, Scholarship	2000
Who's Who Among American Colleges and Universities	2001
Midwest Nursing Research Pediatric Clinical Nurse Specialist Award	2002
Outstanding Graduate Student Award	2002
Jessie Cross Graduate Nursing Scholarship	2002
PhD Fellowship in Nursing	2005-2006
William and Doris Rodie Dissertation Scholarship	2009

TEACHING ASSIGNMENTS

S483 D192	Clinical Nurse Practice Capstone	2003-2004
S484 D193	Research Utilization Seminar	2003-2004

LIST OF COMPLETED MASTER'S STUDIES

Pilot research study: How Parent's Evaluate Self-Esteem in their Non-Verbal Child with
a Disability. Served as Co-investigator of this exempt study using narrative analysis
to study how parents evaluate the self-esteem of their child who is unable to speak
and has a disability.   Spring 2002

LIST OF COMPLETED DOCTORAL STUDIES

Pilot research study: Parent's Likes and Dislikes Regarding their Child's Augmentative
and Assistive Communication (AAC) Device.   Spring 2008

Doctoral Research Study: Family Experiences with Their Child's Use of a Speech
Generating Device   Fall 2009

GUEST LECTURES

C551 Advanced Nursing Care of Children and Families	Fall 2001
Developmental Disabilities	Fall 2003
	Fall 2005

RCDC Core Classes	
The Nurse's Role in the Interdisciplinary Team	Spring 2002
	Fall 2004
	Spring 2006
	Spring 2009
	Fall 2009
Co-morbidities in Developmental Disability	Fall 2007
GI Issues in Developmental Disability	Fall 2007
Health Disparity for Persons with Disabilities	Spring 2008

Integrity Health Care	
Pediatric Assessment and Infusion	March 2003

Ball State University	
Developmental Disabilities	April 2006

SERVICE

Professional Service (state/regional)

Indiana Association of Rehabilitation Nurses Conference Committee	1990-2005
Visiting Nurse Service: Head Checks for Camp	1995
Parkview Manor Nursing Home (Buddy for AIDS patients)	1994-2001

Head Start Physicals	2001
Indiana Partnership for Inclusive Child Care (Advisory Board Member)	2002-2009
Brownie Leader (Troop 775)	2003-2004
Melmedica Children's Home Care Agency (Advisory Board Member)	2003-2006
NACNS Abstract Reviewer	2004-2009
International Journal of Nursing in Intellectual and Developmental Disabilities Manuscript Reviewer	2004-2009
Lippincott Book Reviewer	2005
Sigma Theta Tau International Abstract Reviewer	2005-2008
Association of Rehabilitation Nurses Abstract Reviewer	2005
38th Annual Sigma Theta Tau International Conference Volunteer Moderator	2005
Spinal Cord Injury in Children Review Panel	2005
Evidence Based Nursing and other evidence-based resources Reviewer	2006
MNRS 2007 Pediatric Symposia Abstract Reviewer	2006
Reviewer for Book Chapter: Rehabilitation Nursing, Elsevier Publishing	2006
Understanding Infant Adoption Curriculum Reviewer	2006
Journal of Specialists in Pediatric Nursing Manuscript Reviewer	2007
ASK Advisory Board Member	2007-2009
Executive Board Member	2008-2009
Board Secretary	2008
Development Recruitment and Retention Committee	2008-2009
Chair Elect	2009
Riley Child Development Center Research Committee	2008-2009
Riley Child Development Center Telemedicine Committee	2008-2009

MNRS Pediatric Pre-Conference Committee	2008
Indiana Governors Planning Counsel for Persons with Disabilities Board Member	2009

PROFESSIONAL ACTIVITIES

Continuing Education Courses:

Association of Rehabilitation Nurses Conference, Kansas City, MO	1991
Association of Rehabilitation Nurses Conference, Pittsburg, PA	1992
Association of Rehabilitation Nurses Conference, Denver, CO	1993
Association of Rehabilitation Nurses Conference, Orlando, Fl	1994
Indiana Association of Rehabilitation Nurses: Rehabilitation Nursing Ethics Indianapolis, IN	1995
Association of Rehabilitation Nurses Conference: A Force for the Future, Indianapolis, IN	1995
Indiana Association of Rehabilitation Nurses: Collagen Vascular Disorders, Indianapolis	1996
Indiana Association of Rehabilitation Nurses: Oncology Rehab, Dispelling the Myths, Indianapolis	1996
McGowan Consultants CEU course: Assessing Health Risk In Developmental Disabilities	1997
Indiana Association of Rehabilitation Nurses: VRE: The Superbug Indianapolis, IN	1997
Indiana Association of Rehabilitation Nurses: Infection Control Issues In Rehabilitation, Indianapolis, IN	1997
Indiana Association of Rehabilitation Nurses: Code Stroke Team TPA Use, Indianapolis , IN	1997
Central Indiana Case Management Society: The Challenges of Change in Case Management, Carmel, IN	1998
Indiana Association of Rehabilitation Nurses: The Gamma Knife Indianapolis, IN	1998
Indiana Association of Rehabilitation Nurses: Current Research In Paralysis, Lafayette, IN	1998
Indiana Association of Rehabilitation Nurses: Update on HIV: Today's Picture, Indianapolis, IN	1998
Indiana Association of Rehabilitation Nurses: What's New in Research and Treatment in Rehabilitation: The CAPD Recycler, Indianapolis, IN	1999
Central Indiana Case Management Society: Tools for the New Millenium, Carmel, IN	1999
Indiana Association of Rehabilitation Nurses: Preparing for New Horizons in the Treatment of Spinal Cord Injury, Indianapolis, IN	1999

Association of Rehabilitation Nurse Conference: Choices and
     Challenges: Rehabilitation in the New Millenium
     Reno, NV   2000
Indiana Association of Rehabilitation Nurses: New Innovations
     In the Treatment of Spasticity, Indianapolis, IN   2000
Vizcarra and Associates, PICC Line Placement, Indianapolis, IN   2001
Association of Rehabilitation Nurses: Teleconference: Pain
     Management   2001
Association of Rehabilitation Nurses Conference:
     Kansas City, MO   2002
Clinical Faculty: A New Practice Role, Indiana University
     School of Nursing, Indianapolis, IN   2003
Midwest Nursing Research Society Conference
     Cincinnati, OH   2005
Sigma Theta Tau International Conference
     Indianapolis, IN   2005
Midwest Nursing Research Society Conference
     Milwaukee, WI   2006
Midwest Nursing Research Society Conference
     Omaha, NE   2007
Clarian Health Research Conference
     Indianapolis, IN   2008
Midwest Nursing Research Society Conference
     Indianapolis, IN   2008
Heidegger Institute,
     Indianpolis, IN   2008
Infant Mental Health Conference
     Indianapolis, IN   2008
Progressive Pediatrics
     Indianapolis, IN   2008
Indiana University Law Conference on Autism
     Indianapolis, IN   2009
Institute for Heideggerian Hermeneutical Methodologies
     Indianapolis, IN   2009
Institute for Interpretive Phenomenology
     Indianapolis, IN   2009

PRESENTATIONS

Crisp, C. (1990). *The Hospitalized Child.* Lifelines Children's Rehabilitation Hospital,
     Indianapolis, IN
Crisp, C. (1990) *Developmental Disabilities.* Lifelines Children's Rehabilitation Hospital,
     Indianapolis, IN
Brown-Mayes, K., & Crisp, C. (1991). *Ensuring Growth and Development in the
     Hospitalized Rehabilitation Client,* Kansas City, MO

Crisp, C. (1991). *Rehabilitation Nursing: Actual Case Studies,* Lifelines Children's
    Rehabilitation Conference, Indianapolis, IN
Crisp, C. (1992). *Sexuality and the School-Ager with a Chronic Disability*, Association of
    Rehabilitation Nurse's Conference, Pittsburg, PA
Crisp, C. (1995). *Developing a Comprehensive Orientation Program for Nonlicensed
    Personnel in the Pediatric Rehabilitation Setting.* Association of Rehabilitation
    Nurse's Conference, Indianapolis, IN
Crisp, C. (1999). *Rehabilitation Across the Lifespan Series,* Indiana Association of
    Rehabilitation Nurses, Indianapolis, IN
Crisp, C. (1999). *Head to Toe Pediatric Assessment*, Johnson County Homecare,
    Franklin, IN
Crisp, C. (2000). *Sexuality and the Person with a Traumatic Brain Injury*, Indiana Brain
    Injury Conference, Indianapolis, IN
Crisp, C. (2001). *Age-based Competencies*, Home-Based, Rehab, Indianapolis, IN
Crisp, C. (2001). *Child and Elder Abuse,* Home-Based Rehab, Indianapolis, IN
Crisp, C. (2001). *New Trends in Pediatric Rehabilitation*, Indiana Case Management
    Society, Carmel, IN
Crisp, C. (2002). *The Nurses Role in Sexuality Teaching for Children with Disabilities,*
    Association of Rehabilitation Nurses Conference, Kansas City, MO
Crisp, C. (2003). *Sexuality for Persons with Developmental Disabilities,* Indiana
    Developmental Disabilities Nurse Association, North Vernon, IN
Crisp, C. (2004). *Love in the Afternoon: Sexuality Issues in Disability*, Indiana
    Association.of Rehabilitation Nurses, Shelbyville, IN
Crisp, C. (2005). *Are PEGs Making Dinosaurs of Other Types of Enteral Tubes*, Sigma
    Theta Tau International Conference, Indianapolis, IN
Ellett, M. & Crisp, C. (2006). *Using Algoritms to Improve the Safety and Cost Efficacy of
    Nursing Practice,* Society of Gastroenterology Nurses and Associates, San
    Antonio, TX
Crisp, C. (2007). *Giving a Voice to Those who Cannot Speak*, Indiana University School
    of Nursing Indianapolis, IN
Crisp, C. & Ellett, M. (2007). *Are PEGs Making Dinosaurs of Other Types of Enteral
    Tubes*, Midwest.Nursing Research Society, Omaha, NE
Crisp, C. (2009). *Out of the Chrysalis of Silence and into a World of Possibilities: Family
    Experiences.of Having a Child using a Speech Generating Device,* Institute for
    Interpretive Phenomenology, Indianapolis, IN

PUBLICATIONS

Ailey, S., Marks, B., Crisp, C., & Hahn, J. (2003). Promoting sexuality across the
    lifespan for individuals with intellectual and developmental disabilities. *Nursing
    Clinics of North America, 38*(2), 229-252.
Crisp, C. (Ed), (2003). *Kidbook: A Medical Procedures Manual for Early Care and
    Education Providers for Young Children with Special Healthcare Needs,*
    Indianapolis, IN: Indiana University School of Medicine, Visual Media, Office of
    Information Services and Education Technology.

Crisp, C., Ellett, M., & Tomlin, A. (2003). Modification of the Washington Guide to
    development in the young child. Adapted from Washington, G., Barnard, Kee, K.,
    and Erickson, M. L. (1976). Washington Guide to promoting development of
    young child. In G. Washington, K. Barnard-Kee, and M.L. Erickson (Eds).
    Teaching children with developmental problems (2nd Ed, pp. 294-325). St. Louis:
    Mosby.
Tomlin, A. & Crisp, C. (2004). *ENRICH: Early Childhood Information, Resources, and
    Intervention Curriculum Handbook.* Indianapolis, IN: Indiana University School
    of Medicine, Visual Media, Office of Information Services, and Educational
    Technology.
Crisp, C. (2005). Sometimes I just want to be Mom. *International Journal of Intellectual
    and Developmental Disabilities, 2*(1), online journal http://journal.hsms.org/ijnidd
Crisp, C. (2006). Esophageal nasogastric tube misplacement in an infant following laser
    supraglottoplasty. *Journal of Pediatric Nursing, 21*(6), 454-455.
Crisp, C. (2006). Nasogastric tube insertion in children with neurodevelopmental
    disabilities: Size does matter. *Gastroenterology Nursing, 29*(2), 108-110.
Crisp, C. (2007). The efficacy of intelligence testing in children with physical disabilities,
    visual impairments, and/or the inability to speak. *The International Journal of
    Special Education, 22*(1), 137-144.
Crisp, C. (in review for publication) Effects of augmentative and assistive
    communication on language development in children with a disability
Crisp, C. & Ellett, M. L. (in review for publication). How parents evaluate self esteem
    in their nonverbal child with a disability.

Published Abstracts

Mayes, K. & Crisp, C. (1991). *Ensuring Growth and Development in the
    Hospitalized Rehabilitation Client,* Kansas City, MO
 Crisp, C. (1992). *Sexuality and the School-Ager with a Chronic Disability*, Association
    of Rehabilitation Nurse's Conference, Pittsburg, PA
 Crisp, C. (1995). *Developing a Comprehensive Orientation Program for Nonlicensed
    Personnel in the Pediatric Rehabilitation Setting.* Association of Rehabilitation
    Nurse's Conference, Indianapolis, IN
Crisp, C. (2002). *The Nurses Role in Sexuality Teaching for Children with Disabilities,*
    Association of Rehabilitation Nurses Conference, Kansas City, MO
Crisp, C. (2005). *Are PEGs Making Dinosaurs of Other Types of Enteral Tubes*, Sigma
    Theta Tau International Conference, Indianapolis, IN
Ellett, M. & Crisp, C. (2006). *Using Algoritms to Improve the Safety and Cost Efficacy of
    Nursing Practice,* Society of Gastroenterology Nurses and Associates, San
    Antonio, TX
Crisp, C. (2007). *Are PEGs Making Dinosaurs of Other Types of Enteral Tubes.* Midwest
    Nursing Research Society Conference, Omaha, NE
Crisp, C. (2009). *Out of the Chrysalis of Silence and into a World of Possibilities: Family
    Experiences of Having a Child using a Speech Generating Device,* Institute for
    Interpretive Phenomenology, Indianapolis, IN