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Managing the Healthcare Needs of Adolescents with Autism Spectrum Disorder: The Parents'
Experience

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of
Philosophy at Virginia Commonwealth University.

by

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Abstract

MANAGING THE HEALTHCARE NEEDS OF ADOLESCENTS WITH AUTISM SPECTRUM DISORDER: THE PARENTS' EXPERIENCE

By Julie A. Strunk, MSN, RN

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University.

Virginia Commonwealth University, 2011

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The purpose of this phenomenological study was to describe the experiences of parents who manage the health needs of an adolescent with Autism Spectrum Disorder (ASD). Qualitative interviews were conducted with parents from 10 families of adolescents with ASD residing in Virginia. Data were analyzed using Clark Moustakas' method of analysis of data in which the phenomenologist asks the following questions: What are the individual's experiences, and in what context did they experience them? This study maximized credibility by using three strategies: prolonged engagement, peer debriefing, and member checking. "Parents needing help" emerged as the essence of the parents' experiences. Four themes representing the essential challenging elements of the parents' experiences included concern with medications, frustrations with healthcare services, recognizing secondary health issues, and the need for resources and services. Findings of the current study revealed key factors to be considered in the development and delivery of help in managing the adolescent with ASD healthcare needs. These included providing

guidelines for primary care providers, increasing the healthcare provider's awareness and understanding of ASD, and increasing the number of resources for parents of adolescents with ASD. The results of the study confirmed that managing the adolescent's healthcare needs was frustrating and challenging and that parents had a need for help in managing these needs. Nurses can be integral in helping parents to overcome frustrations and challenges by becoming more aware of the ASD spectrum of neurobiological disorders, by creating and planning interventions for parents, by sharing information regarding resources and services, and by collaborating with others in the healthcare field to provide services for adolescents and their families. Additional research, both qualitative and quantitative is needed to understand how both parents and adolescents with ASD experience this transitional period.

Keywords: Autism spectrum disorder, parents, healthcare needs, adolescents with autism

Chapter One

Parenting an adolescent with Autism Spectrum Disorder (ASD) can be a challenging and unique experience when dealing with the child's healthcare needs. Children with ASDs often have multiple needs, including comorbid medical conditions, mental health issues, and developmental delays, that bring them to their primary care physician more frequently than other children (Brachlow, Ness, McPheeter, & Gurney, 2007; Gurney, McPheeter, & Davis, 2006). Parents often look to their primary healthcare provider to provide guidance in navigating specialty care such as psychopharmacologic and behavioral interventions, educational and rehabilitation therapies, and complementary and alternative medicines. However, it has been reported that parents of children with ASD experience challenges when accessing healthcare for their child and a dissatisfaction with treatment and guidance (Carbone, Behl, Azor, & Murphy, 2010; Harguanani, Shipman, & Reynolds, 2006). Parents have also reported a lack of advocacy for special services as well as a lack of expertise in the care of children with ASD (Brachlow et al., 2007; Carbone et al., 2010; Harguanani et al., 2006). Myers and Johnson (2007) reported that even pediatricians perceive a lack of necessary skills needed to provide the appropriate care for children with ASDs. Unfortunately there seems to be discrepancies between physician and parent perceptions of the primary care needs of children with ASDs (Carbone et al., 2010). Therefore, the aim of this study was to examine the parent's experience of managing the healthcare needs of the adolescent with ASD.

Chapter Two

Dissertation Proposal

Julie A. Strunk

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Dissertation Proposal

I. Aim of Study

A. Phenomenon of Interest

The aim of this study is to examine the parent's experience of managing the healthcare needs of the adolescent with Autism Spectrum Disorder (ASD). Parenting an adolescent with ASD can be a challenging and unique experience. Autism is considered the fastest growing developmental disability in the nation, affecting one out of every 150 children and is now considered to be the third most common childhood disorder, more common than Down syndrome and childhood diabetes combined (CDC, 2010). It occurs more frequently than childhood cancer, cystic fibrosis, and multiple sclerosis together (Autism Society of American, 2009). An estimated 1.5 million individuals in the U.S. and tens of millions worldwide are affected by autism and government statistics suggest the prevalence rate of autism is increasing 10-17 percent annually (CDC, 2010). There is no established explanation for this increase, although improved diagnosis and environmental influences are two reasons often cited.

B. Perceived Justification for Studying the Phenomenon

After performing an integrative review on the perceptions of parents of children with ASD, it was found that two major themes emerged: stress and the need for social support. No studies were found that reflected the parent's perception or experience of managing the healthcare needs of the adolescent with ASD. While the profession of nursing has had a long history in the care and advocacy of vulnerable populations, including parents of children with disabilities, no articles were found in the current nursing literature that address a parent's perception of meeting the health care needs of the adolescent who has autism. Evidence-based nursing practice dictates the use of applying best practices to any decisions involving the care of

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individual clients. This includes ensuring delivery of healthcare services to the most vulnerable populations, which would encompass parents of adolescents with ASD. With the increasing numbers of children being diagnosed with ASD and with autism becoming a prominent topic in the health and educational fields, the importance of exploring the lived experience of those parents managing the healthcare needs of the ASD adolescent cannot be over stated. It is only from hearing their individual stories that researchers can discover how to work with and provide services for these individuals.

C. Phenomenon Discussed within a Specific Context: Lived Experience

When individuals relate their story of a lived experience and that story is accepted and recorded verbatim, the words become empowering, allowing for freedom of expression in meaning (Lindseth & Norberg, 2004). The narration tells the experience of being-in-the-experience, the truth. Through lived discourses, researchers participate in the experience, and through stories or narrations they become aware of what it's like for the individuals telling the story to participate in that experience (Lindseth & Norberg, 2004). Narratives or stories can touch and move individuals when exposure to the experience occurs. Thus being touched and moved may reveal the essential meaning of the experience (Lindseth & Norberg, 2004). According to Lindseth and Norberg (2004), being touched and moved by essential meaning leads to truth as opposed to correctness, and provides connection to the ontological level of the life world. Truth and connectedness can only be fulfilled through understanding the experience (Lindseth and Norberg, 2004).

D. Assumptions and Biases Related to the Study of the Phenomenon

An adolescent's autism diagnosis affects every member of the family in numerous ways (Beresford, 1994; Prilleltensky and Nelson, 2000; Strunk, 2010). Parents and/or caregivers often

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place their primary focus on helping their adolescent with ASD, which may put strains on their marriage, other children, work, finances, and personal relationships and responsibilities (Raina, O'Donnell, Schwellnus, Rosenbaum, King, Brehaut, Russell, Swinton, King, Wong, Walter, & Wood, 2004; Strunk, 2010). Parents have to shift much of their resources of time and money towards providing treatment and interventions for their adolescents, to the exclusion of other priorities (Raina et al., 2004).

Adolescents with ASD often suffer from co-morbidities such as tuberous sclerosis complex, fragile x syndrome, Down syndrome, and Prader-Willi syndrome to name a few (Zafeiriou, Ververi, Vargiami, 2007). These individuals usually display problems related to neurologic issues as well as nutritional, gastrointestinal and orthopedic problems (Souder, DePaul, Freeman, & Levy, 2002; Strunk, 2009). Due to the lack of specific pathophysiology, adolescents with ASD are often treated based on their symptomology and many are on a plethora of medications (Cole, 2008; Strunk, 2009).

It should be kept in mind that adolescents with autism have the same basic healthcare needs as those adolescents who are without disabilities (Cole, 2008; Strunk, 2009). Many are susceptible to risky health behaviors such as exploration and experimentation with smoking, alcohol, and drug use (Klein & Wilson, 2002). They also experience high levels of stress, decreased physical activity, unsafe sexual activity, depression, and suicide (Klein & Wilson, 2002). Therefore, the behavioral and medical needs of an adolescent with ASD can complicate familial relationships, creating a stressful environment in which to live and function in.

E. The Method of Inquiry

The purpose of the phenomenological approach is to illuminate and identify phenomena through how they are perceived by individuals in a specific situation (in this case, a parent's

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experience in managing the healthcare needs of the adolescent with ASD) (Creswell, 2007). This is accomplished through inductive, qualitative methods such as interviews, discussions and participant observation, and representing it from the perspective of the research participant(s) (Creswell, 2007). Phenomenology is concerned with the study of experience from the perspective of the individual, 'bracketing' taken-for-granted assumptions and usual ways of perceiving (Creswell, 2007). Ontologically, human experience is considered to be preeminent and fundamental, and reality is measured as the whole experience that is detailed in thinking, feeling, and willing (Mitchell & Cody, 1999). Epistemologically, phenomenological approaches are based in a paradigm of personal knowledge and subjectivity, and emphasize the importance of the personal perspective and interpretation (Creswell, 2007). This personal perspective and interpretation are of great importance for understanding the subjective experience such as the parent with an adolescent with ASD; gaining insights into people's motivations and actions by exploring how the parent manages the adolescent's healthcare needs; and cutting through the clutter of taken-for-granted assumptions by taking into account the healthcare needs of the adolescent with ASD (Creswell, 2007).

Evolution of the Study

A. Historical Context

Family plays an important part in the environment of the adolescent and is central in their developmental outcomes (Sameroff, 1990; Altieri & von Kluge, 2009). According to Olson and colleagues (1985) and Seligman & Darling (1997), a well-functioning family has a good balance of cohesiveness and adaptability. Cohesion, as defined by Olsen (1985), is the emotional bonding between family members. Adaptability is defined as the family's ability to change in response to a stressful situation (Olsen, 1985). When there is an upset in the balance of cohesion and

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adaptability of a family, their functioning styles tend to change. Most families rely on social support, learn coping behaviors, and change the way an experience is interpreted in order to refurbish the balance in the family system (Patterson 1988; Altieri & von Kluge, 2009).

Although families may typically establish their functional styles early, these functional styles change significantly upon discovery that their child has a disability (Altieri & von Kluge, 2009). Families who have a child with autism often experience a change in their functional styles due to the ambiguity of the diagnosis, the severity and duration of the disorder, and the child's lack of adherence to social norms (Bristol, 1984; Altieri & von Kluge, 2009)

B. Experiential Context

As a parent of neurotypical adolescent children, I have experienced the normal frustrations of stress, financial burden and lack of social support. I have also experienced many joys and blessings. As a nurse and educator, I have experienced working with autistic adolescents and their parents and have observed parental behaviors that would lead me to believe that their lives are stressful, that they suffer from financial burdens, and that there is little if any social support. These families seem to have difficulties managing their adolescent's behavior, healthcare needs, and educational needs.

C. Summary

The family plays an important role in the life of an adolescent, whether neurotypical or disabled. Autism presents unique challenges to the family in their ability to function. Therefore, it is of interest to look at the lived experience of the parent managing the healthcare needs of the adolescent with autism, to understand their experience, and to make meaning of it.

III. The Method of Inquiry: Moustakas' Method

A. Introduction to the Phenomenological Approach

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Phenomenological research in nursing is one of several methods that can be used to explore the experiences of others. Although some may argue that this method lacks empirical clarity, others can definitely attest to its very roots of scientific research. Those who choose to write through the lens of phenomenology tend to focus on describing what groups or participants have in common as they experience a particular phenomenon (Creswell, 2007). Various approaches within phenomenology can be used to guide the research. Since there is more than one legitimate way to proceed with a phenomenological investigation, the nursing researcher should be familiar with his or her philosophic underpinnings and ground the study in the approach that would offer the most rigorous and accurate interpretation of the phenomenon under investigation.

In order to apply phenomenology in an unbiased manner, one needs to examine the research approach. Basically the principles one must apply consist of starting without a hypothesis or theoretical model; however, the goal is to come as close to understanding the lived experience as possible. The problem and question formulation guides the focus of the investigation, therefore questions should be open ended and asked in such a way that they are understandable to others (Kakulu, Byrne, Viitanen, 2009). The outcome of the process is in obtaining the description of the phenomenon. The researcher must apprehend and understand the lived context of the person and their experience (Creswell, 2007). Therefore, data generating and data collection involve inquiry and dialoguing with individuals. Data analysis occurs when the collected data is read and scrutinized so as to reveal the structure, meaning, pattern, and consistency of the shared experience (Kakulu et al., 2009).

There are certain stages taken in phenomenological research that makes it distinct from other research methods. The first stage is known as the 'epoche' that means learning to look at

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things in such a way that what are seen are only what stands before one's eyes (Creswell, 2007). The epoche then is what can be described and defined. Along with the stage of the epoche is the notion of bracketing. Bracketing is suspending or setting aside biases and everyday understandings, theories, beliefs, assumptions, and judgments (Daniels, 2005). Bracketing allows the researcher to be as open as possible to what the individual wants to share. The second stage in the phenomenological process is known as reduction. This involves reading through the transcripts of interviews, field notes, etc. and then listing or clustering these meanings into units or themes (Kakulu et al., 2009). The third stage is known as imaginative variation in which an analysis is done to facilitate the development of textual and structural descriptions of the experience and the meanings and essences that appear (Kakulu et al., 2009). The last stage is known as the synthesis of meaning. From the textural descriptions that emerge, the researcher is then able to integrate the textures and structures in order to construct the essence of the phenomenon (Kakulu et al., 2009).

B. Moustakas' Method

Moustakas, a transcendentalist, indicated that the steps he used in phenomenological data analysis were more structured in their approach than what was employed by the hermeneutical phenomenologists (Moustakas, 1994). The transcendental approach balances both the objective and subjective approaches to knowledge and detailed, rigorous data analysis steps (Moere-Urdahl & Creswell, 2004). The two central questions that Moustakas recommended that phenomenologists ask were: What are the individuals' experiences and in what context or situations do they experience it? Moustakas' approach focused on the wholeness of the experience and searched for the essences of the experiences (Moustakas, 1994). According to Moustakas (1994), the phenomenological approach involved a return to the experience in order

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to obtain comprehensive description that provided the basis for portraying the essence of the experience. The researcher should refrain from making suppositions, focus on the topic freshly and naively, construct a problem or question that guides the study, and derive findings that would provide the basis for further reflection and research (Moustakas, 1994).

When analyzing the data, one follows a systematic procedure where the researcher describes his or her own experiences with the phenomenon (epoche), identifies any significant statements in the database from the participants, and then clusters the statements into meaning units and themes. The researcher then synthesizes the themes into a description of the experiences of the participants (using both textural and structural descriptions), and then constructs a combined description of the meanings and essences of the experience (Moerer-Urdahl & Creswell, 2004).

Moustakas' approach is consistent with human science research because he relies on the individual experience told from the participants' voices and not from the research, or from individuals reporting the studies in the literature (Moerer-Urdahl & Creswell, 2004). Moustakas' method has been found to be more easily understood and applicable to the novice researcher (Moerer-Urdahl & Creswell, 2004), and his method allows the participants to be illuminated concerning the research process (Moustakas, 1990). His method provides a systematic approach to analyzing data about the lived experience (Moustakas, 1990). However, it should be noted that Moustakas' method is not without weaknesses. Although the analysis process proceeds from the detailed to the more general, checks are not built into the analysis to make sure that a flow actually occurs (Moerer-Urdahl & Creswell, 2004). The essence of any experience may never be totally exhausted and the process of epoche is often difficult to achieve because the researcher may not be able to completely set aside all biases and assumptions (Moerer-Urdahl &

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Creswell, 2004). Finally, there is an absence of reflection on the historical, cultural, and social contexts in which the reader understands and interprets (Moerer-Urdahl & Creswell, 2004).

C. Rationale for Selection of the Phenomenological Method

Using description would allow the researcher to use language that articulates the parent's experience of managing the healthcare needs of an adolescent with ASD. Through description, the researcher includes explanations, constructions, and interpretations in order to articulate what has been experienced (Giorgi, 1997). Experiences become the basic data from which the nurse researcher works. According to Husserl (1970), the search for that experience, or essence, allows the researcher to present what has been found by others. The experience, or essence, is that which holds the parts or aspects of the phenomenon together (Giorgi, 1997). Through sharing the experience, the researcher continually looks for themes that have interconnectedness. Although the experiences of another cannot be known, the attitude should be that of wanting to understand the individual's world through their eyes and their experiences as far as possible. Together, the researcher and the individual can then probe those experiences fully and understand them (Daniels, 2005). When the researcher uses the phenomenological method, he or she must continually examine and reexamine their biases and presuppositions (Daniels, 2005).

D. Outcome of Using the Method

Through the use of Moustakas' method, there will be a better understanding of the lived experience of parents who manage their ASD adolescent's healthcare needs and to allow the investigator to understand the meaning of the totality of the experience. This is important because there have been no other studies examining this issue.

E. Background of the Method

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Phenomenology is rooted in the philosophical traditions developed by Husserl, Merleau-Ponty, and Heidegger and is a method used to reflect on the experiences of individuals (Creswell, 2007). Phenomenology seeks to describe what individuals have in common as they experience a phenomenon. To this end, qualitative researchers identify a phenomenon to research through the following: through a description of the immediate experience; through an attempt to capture experience as lived, through descriptive analysis; through a method of knowing that begins with things themselves, and then opens up to the freedom of perceptions and interpretations; and through a method of learning about another person by listening to their descriptions of what their subjective world is like, and then trying to understand those meanings through the researcher's eyes (Daniels, 2005).

IV. Moustakas' Phenomenological Approach: General

A. Turning to the Nature of the Lived Experience

According to Moustakas, the nature of the lived experience allows the individual to focus on seeing, listening, touching, and thinking on what that experience is in its essences (Moustakas, 1994). The researcher can examine the experience for what it is, under what conditions it occurs, from what frame of reference, and what its possible meanings are (Moustakas, 1994). By turning to the lived experience, the researcher can describe in detail the whole account of an issue, problem, situation, or experience, using qualities and properties from specific contexts or perspectives, so that the experience takes on a vivid or essential meaning, a clear picture of what is (Moustakas, 1994).

B. Transcendental Investigation

Transcendental investigation attempts to describe an experience as it is evident to the individual (Husserl, 1970). It seeks to circumvent any presuppositions placed on the experience

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in advance, whether sociocultural or scientific (Husserl, 1970). The aim of transcendental investigation is to go back to the experience itself, the essence of the experience before it has been filtered through the individual's perceptions of it (Husserl, 1970).

C. Sample

Phenomenological studies do not require a specific number of participants. More importantly, phenomenological studies need to have enough participants to adequately explore the phenomenon being studied. Creswell (1998) recommended that the phenomenologist interview a small number of individuals, no more than 10. With this in mind, 10 parents (mother, father, or both) of adolescents (between the ages of 10 to 20) with Autism Spectrum Disorder will be interviewed for this study. Moustakas (1994) recommended participants are selected according to two criteria: (a) they are experiencing the phenomenon being studied, and (b) they are willing to participate in the study and willing to be interviewed. Parents will be purposefully chosen to participate in this study because of their experience in managing the healthcare needs of an adolescent who has ASD and their willingness to share their experience.

D. Setting/Access

Participants will be recruited from the Faison School of Autism and the Medical College of Virginia Children's Pavilion through the use of printed flyers publicizing the proposed study. Prospective participants will be given a letter explaining the nature of the study and a consent form. The letter will include a description of the study, the purpose, and procedures. The letter and informed consent will be mailed with a request to return the consent form to the researcher's mailbox if they are willing to participate. An appointment will be scheduled with each participant for a time that suits that individual's schedule. The interviews will take place in a quiet office in the school of nursing at Virginia Commonwealth University or at the Faison

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School of Autism. Participants will be expected to provide their own childcare as interviews will take place without their children being present. Each interview will be audiotaped. The length of interviews will vary depending on the amount of information that each participant is willing to share and should not exceed three hours. Inclusion criteria include: (a) must be the parent of an adolescent between the ages of 10 and 20, with a diagnosis of Autism Spectrum Disorder; (b) the parent/s must speak English and be a resident of the state of Virginia; (c) adolescent must have at least one co-morbidity; (d) adolescent must have at least one problem with either a neurological, gastrointestinal, or orthopedic issue; and (e) adolescent must be experiencing or have experienced puberty. Exclusion criteria include: (a) parents who are not the primary caregiver of the adolescent; and (b) parents of ASD adolescents who are adopted.

E. Interviewing/Fieldwork

The interview will be an interactive process between the participant and the researcher. The questions will be open ended and follow-up questions will be used to assist in clarifying and understanding the information presented. A general guide of questions will include asking participants what it is like managing the healthcare needs of an adolescent with ASD and how this affects them and those in their immediate family.

F. Information Collection, Storage Analyzed

Each participant will be informed that the information will be shared with the public by a written manuscript that will be submitted to a peer-reviewed journal. Participants will be assured that all identifying information will be removed. Tapes, notes, and other interview material will be stored in a locked cabinet in the researcher's office. The researcher will hire a transcriber who will be required to complete CITI training through VCU's IRB. He or she will then be allowed to transcribe the audiotapes. A master copy of the transcriptions will be stored at the

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VCU School of Nursing for safety purposes. The researcher will use one working copy of the transcriptions.

G. Human Subject Considerations

Participant confidentiality will be established by following the safeguards as approved by the Virginia Commonwealth University Institutional Review Board. The participants will be assigned a pseudonym to protect their identity. The researcher will maintain all data including audio recordings, and all copies of the transcripts in a secure, locked storage at the School of Nursing. At the completion of the study, data will be stored securely at the School of Nursing and destroyed after 7 years in compliance with VCU policies. The audio tapes will be destroyed upon completion of the study. The transcriber will be instructed on the importance of participant privacy; the transcriber will have completed the CITI training. All participants must sign a consent form, assuring that they understand the nature and purpose of the study. The participants will be assured that their participation in the study is completely voluntary. Neither the participants, nor the researcher, will receive compensation for their involvement in this study.

H. Phenomenological Reflection

The purpose of phenomenological reflection is to try to grasp the meaning of something (van Manen, 1997). The insight into the essence of a phenomenon involves a process of reflecting on and clarifying the meaning of the lived experience (van Manen, 1997). Therefore, when I reflect on the experience of a parent managing the healthcare needs of an adolescent with autism, I will not reflect on it as a researcher or a nurse or a phenomenologist. Rather, I will reflect phenomenologically on the experiences of parenting as a parent. In other words, I will attempt to grasp the pedagogical essence to that particular experience (van Manen, 1997).

I. Phenomenological Writing

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In phenomenology, to explore is to reflect is to think is to write and to write is to put thought on paper (van Manen, 1997). It is inextricably linked with reflection (van Manen, 1997). It is when the questions and thoughts being asked of the phenomena presented in the experience are assembled on paper, that the researcher has opportunity to step back and reflect (van Manen, 1997). The role of phenomenological writing is to convey meaning in description of phenomena keeping in mind that there is no one definitive meaning and that discovering the essence of the phenomenon is the ultimate goal (van Manen, 1997). Writing describes the richness of the phenomena within the lived experience. It allows the writer to put form and shape to their thoughts. Giorgi (1997) states, "To describe means to give linguistic expression to the object of any given act precisely as it appears....to communicate to others the objects of consciousness to which one is present, precisely as they are presented."

Writing is both the process and product of phenomenological inquiry in which the writer writes to inquire of phenomena in the lived world as well as writing to communicate to others the discoveries resulting from the inquiry (van Manen, 1997). Phenomenological writing has the intent of having individuals see what hasn't been seen before, of showing the phenomenon in a new way (van Manen, 1997).

J. Reliability and Validity

This study will strive to establish trustworthiness by including credibility, transferability, dependability, and confirmability. Credibility is enhanced by the following techniques: (a) prolonged engagement, (b) triangulation, (c) peer debriefing, (d) negative case analysis, (e) referential adequacy, and (f) member checking. This study will maximize credibility by using three of these strategies: prolonged engagement, peer debriefing, and member checking.

Prolonged engagement requires that the researcher use extended time to reflect on

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journals and field notes and test how their perceptions of the experience have changed over that extended time frame. According to Guba (1981), researchers need to be able to show that sufficient time was spent in the field in order to justify their characterizations of the experience. In this case, the student researcher will spend at least three hours with each participant in the interview session and in additional time spent reading, thinking about, and analyzing the data.

Peer debriefing requires that the researcher select one or more peers who will serve as a guide and discuss interpretations and concerns with those colleagues. According to Guba (1981), it is important for researchers to regularly detach themselves from the field, and to seek counsel from other professionals who are willing to perform the debriefing function. In this case, the student researcher has a doctoral colleague who is willing to read and discuss interpretations as well as concerns about the research process.

Member checking requires that the researcher obtain feedback from the research participants (Lincoln & Guba, 1985). This feedback is particularly useful when the analysis and interpretation have been made and conclusions have been drawn (Tutty, Rothery, & Grinnell, 1996; Guba, 1981). In this case, the student researcher will invite the participants to read the final manuscript in order to allow for any changes that need to be made and to affirm that what has been written is correct.

The responsibility for transferability falls not only on the original researcher but on the person seeking to apply the information (Lincoln and Guba, 1985). The prospective study may have transferability to other parents who manage the healthcare needs of their adolescent with ASD; ultimately, it is up to the individual seeking the application to determine if the data is applicable. The researcher can facilitate transferability by providing thick descriptions from the participants' words and providing rich narratives of their experiences. Dependability will be

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achieved by maintaining an inquiry audit (Lincoln and Guba, 1985). This audit will consist of examining the data-collection process and the data analysis process by keeping a reflexive journal, maintaining a notebook with transcripts and the researcher's reactions and thoughts, and consulting an experienced and qualified outside expert to review or audit the consistency of the research process.

To enhance confirmability an audit-trail record will be created during each phase of the data collection and data analysis process (Lincoln and Guba, 1985). It will consist of the following: (1) raw data, interview, audiotapes, transcripts; (2) data-analysis materials such as write-ups, interview notes, results, findings, interpretations, themes, definitions; (3) all process notes describing methodology and trustworthiness; and (4) all materials concerning expectations, predictions and intentions, question development and data collection. At the completion of this study, the principal investigator will examine the audit trail and verify whether procedures were followed and interpretations were reasonable (Guba, 1981).

The final technique is reflexive journaling. The researcher will maintain a daily journal that includes biases, thoughts, reflections, daily schedules, and a methodological log. It is important to recognize that a reflective level of self-awareness and self-consciousness is required to begin to capture the perspectives through which the world is viewed and that it may be impossible to take hold of the unconscious filters through which we experience events (Bell & Newby, 1977; Bell & Roberts, 1984; Mauthner & Doucet, 2003). No matter how aware and reflexive the student researcher tries to be, as Grosz (1995: 13) points out, 'the author's intentions, emotions, psyche, and interiority are not only inaccessible to readers, they are likely to be inaccessible to the author as well' (Mauthner & Doucet, 200).

Chapter Three

Children with Autism Spectrum Disorder and its Effect on Parents: An Integrative Review

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Abstract

PURPOSE This study aims to describe the current research literature on children with autism spectrum disorder and its effects on parents.

DESIGN AND METHODS Twenty-four articles were identified as the basis of this review using Cooper's methodology (1998) for synthesizing research. Articles were categorized according to the levels of evidence proposed by Melnyk and Fineout-Overholt (2005).

RESULTS All of the studies included in this review reported that most parents in general experienced some level of stress in their lives either related to their child's diagnosis or behaviors exhibited by the child. Stress was also equated with the family's ability to accommodate their autistic child's needs in the home, maternal caregiving, and family functioning related to social support. There were no studies that examined the overall lived experience of having a child with an ASD.

RESEARCH IMPLICATIONS More qualitative research is needed to elicit the meaning of the relational and contextual factors affecting parents who have a child with Autism Spectrum Disorder. Qualitative approaches, including open-ended interviews, would allow for interaction between the participants and the researcher and would allow the investigator to understand the meaning of the totality of the experience of parents having a child with an ASD, a phenomenon still requiring further research.

Search terms: ASD, autism, parents, lived experience, attitudes toward illness

Introduction

Parenting a child with an autism spectrum disorder (ASD) can be a challenging and unique experience. Autism is now considered the fastest growing developmental disability in the nation, affecting one in 150 children and is the third most common childhood disorder, more common than Down Syndrome and childhood diabetes combined (CDC, 2010). It occurs more frequently than childhood cancer, cystic fibrosis, and multiple sclerosis together (Autism Society of American, 2009). An estimated 1.5 million individuals in the U.S. and tens of millions worldwide are affected by autism and government statistics suggest the prevalence rate of autism is increasing 10-17 percent annually (CDC, 2010). There is no established explanation for this increase, although improved diagnosis and environmental influences are two reasons often considered.

Family plays an important part in the environment of the child and is central in their developmental outcomes (Sameroff, 1990; Altieri & von Kluge, 2009). According to Olson and colleagues (1985) and Seligman & Darling (1997), a well-functioning family has a good balance of cohesiveness and adaptability. Although families may typically establish their functional styles early, it is most likely that these functional styles change significantly upon discovery that their child has a disability (Altieri & von Kluge, 2009). As the functioning of the family affects the child, the development of the child affects the functioning of the family (Altieri & von Kluge, 2009). Although a review of the literature determined there were no published studies on the lived experience of parents who have a child or children with ASD, this paper will examine the related literature including those articles that addressed parental stress, maternal distress, and family functioning when a child in the family has autism.

Background

Many scholars have found that parenting a child with an ASD can be very stressful because of the number and nature of symptoms associated with the disorder. Parents often experience significant challenges with their child's inability to communicate effectively and their difficulty in learning (Phetrasuwan & Miles, 2009). In conjunction with these difficulties, parents are required to be vigilant about and manage inappropriate and sometimes aggressive or violent behaviors (Phetrasuwan & Miles, 2009). Extra care is needed due to the child's lack of self-care skills and ongoing dependency needs (Phetrasuwan & Miles, 2009). Advocacy for the child is often needed within the school, medical setting, and social setting (Phetrasuwan & Miles, 2009). Often times, parents may experience stigma from society (Gray, 1993), and worry about their child's future for independent living (Koegel, Schreibman, Loos, Dirlich-Wilhelm, Dunlap, Robbins, et al., 1992; Little & Clark, 2006).

In response to these identified challenges, previous researchers have suggested examining (a) parental stress; (b) perceptions of caregivers; (c) family functioning and coping; and (d) adverse effects on mothers (Phetrasuwan & Miles, 2009; Higgins, Bailey, & Pearce, 2005; Lee, Lopata, Volker, Thomeer, Nida, et al., 2009; Kelly, Garnett, Attwood, & Peterson, 2008; Altieri & von Kluge, 2009).

While the profession of nursing has had a long history in the care and advocacy of vulnerable populations, including parents of children with disabilities, no articles were found in the nursing literature that addressed the lived experience of parents who have a child with an autism spectrum disorder. Evidence-based nursing practice must conscientiously use the current best evidence in making decisions about the care of individual clients and the delivery of

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healthcare services to the most vulnerable, including parents of children who have an autism spectrum disorder.

Definition

Autism Spectrum Disorder is a general term used to describe a group of complex developmental brain disorders known as Pervasive Developmental Disorders (PDD). The other pervasive developmental disorders are PDD-NOS (Pervasive Developmental Disorder – Not Otherwise Specified), Asperger's Syndrome, Rett Syndrome and Childhood Disintegrative Disorder. The main signs and symptoms of autism involve problems in the following areas:

- Communication - both verbal (spoken) and non-verbal (unspoken, such as pointing, eye contact, and smiling)
- Social - such as sharing emotions, understanding how others think and feel, and holding a conversation
- Routines or repetitive behaviors (also called stereotyped behaviors) - such as repeating words or actions, obsessively following routines or schedules, and playing in repetitive ways

ASDs begin before the age of 3 and last throughout a person's life, although symptoms may improve over time. Some children with an ASD show hints of future problems within the first few months of life. In others, symptoms might not appear until 24 months or later. Some children with an ASD seem to develop normally until around 18 to 24 months of age and then they stop gaining new skills, or they lose the skills they once had (Lord, Risi, DiLavore, Shulman, Thurm, & Pickles, 2006). Diagnosing ASDs can be difficult since there is no medical test to diagnose the disorders. Health care providers examine the child's behavior and development to make a diagnosis. ASDs can sometimes be detected at 18 months or younger.

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By age 2, a diagnosis by an experienced professional can be considered very reliable (Lord, Risi, DiLavore, Shulman, Thurm, & Pickles, 2006). However, many children do not receive a final diagnosis until they are much older. This delay means that children with an ASD might not receive the help they need.

ASDs occur in all racial, ethnic, and socioeconomic groups, but are four times more likely to occur in boys than in girls. The CDC (2010) has estimated that between about 1 in 80 and 1 in 240, with an average of 1 in 110, children in the United States have an ASD.

Methodology

Target Population for Review

The target focus for this integrative review consisted of salient research articles in CINAHL, PubMed, Google Scholar, and PsychInfo databases published from 2000 to 2010 that investigated the relationship between children with autism and their parents. Both quantitative and qualitative studies were reviewed.

Methodology and Data Collection

A classic methodology of the integrative process was used. This process was based on Cooper's five stages of research synthesis, which include: (a) problem formulation; (b) data collection, or the literature search; (c) data evaluation, or the assessment of the quality of studies; (d) analysis and interpretation; and (e) presentation of the results (1998). The goal of this review was to summarize the accumulated state of knowledge concerning the concept of interest and to highlight important issues that the research has left unresolved. Implications for further research can then be determined.

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Inclusion criteria for this review included the following: (a) the report must have been research based and published in a peer-reviewed journal; (b) the method of data collection and analysis must have been reported, even if descriptions were missing or incomplete; and (c) the report must have been published in the English language, between 2000 and 2010. This time frame permitted the latest evidence in the research literature to be reviewed for the purposes of this study.

Exclusion criteria consisted of articles representing discussions or opinions that did not present original research. Also excluded were reports that consisted of studies relating to screening and diagnosis of autism, caregiver support, interventions, and educational support. Additionally, this review excluded reports based on community resources, and sibling interactions.

Retrieval Methodology

To locate studies from the databases, a combination of keywords that included “ASD,” “autism,” “parents,” “lived experience” and “attitudes towards illness” were used alone and in combination. Each article was reviewed for potential inclusion in this review. Book chapters and letters to the editor were not reviewed. Each study was read initially to identify purpose and to become immersed in the current research literature. A systematic approach to analysis was performed as recommended by Cooper (1998). In the final selection, 21 articles were identified as the basis of the integrative review.

After the studies were identified and reviewed, they were categorized according to a rating system for the hierarchy of evidence, as defined by Melnyk and Fineout-Overholt (2005). A summary of the levels of evidence and articles reviewed are presented in Table 1.

Results

A total of 52 research articles were initially identified. Thirty-one articles were discarded because they did not meet the inclusion criteria. In the final analysis, all studies included variables of “ASD,” “autism,” “parents,” and “attitudes towards illness.” Table 2 is a summary of the 21 research articles reviewed for this investigation, including the sample, levels of evidence, variables, and research outcomes.

The majority of the studies included participants from the United States with the remainder taking place in Belgium, England, Australia, and Scotland. Participants of different racial and ethnic backgrounds were also evaluated, including Caucasians, African Americans, Asians and Hispanics. Study participants included both males and females with diverse socioeconomic status. Eleven of the studies addressed parental stress (Estes, Munson, Dawson, Koehler, Zhou, & Abbott, 2009; Brobst, Clopton, & Hendrick, 2009; Pottie, Cohen, & Ingram, 2008; Phetrasuwan & Miles, 2009; Schieve, Blumber, Rice, Visser, & Boyle, 2007; Phelps, McCammon, Wuensch, & Golden, 2009; Rao & Beidel, 2009; Lee, Lopata, Volker, Thomeer, Nida, Toomey, Chow, & Smerbeck, 2009; Benson, 2006; Davis & Carter, 2008; Brobst, Clopton, & Hendrick, 2009). Seven of the studies addressed the affects of ASD on mothers (Hoffman, Sweeney, Hodge, Lopez-Wagner, Looney, 2009; Hastings Kovshoff, Ward, degli Espinosa, Brown, & Remington, 2005; Larson, 2005; Hoffman, Sweeney, Lopez-Wagner, Hodge, Nam, & Botts, 2008; Eisenhower, Baker, & Blacher, 2005; Dale, Jahoda, & Knott, 2006; Wachtel & Carter, 2008). Three of the studies focused on social support of the parent having a child with an ASD (Altiere & von Kluge, 2009; Tobing & Glenwick, 2006; Giarelli, Souders, Pinto-Martin, Bloch, & Levy, 2005).

Discussion

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This integrative literature review did not reveal any studies that examined the lived experience of parents of children with autism spectrum disorder. One study examined the lived experience of parents who had a downstairs room for their autistic child but this study did not meet selection criteria because it dealt with the child's perception of personal space and emotional space and was therefore discarded.

This integrative review resulted in identification of three prevalent themes that were related to parents having a child with autism. These themes included: parental stress, maternal stress, and the need for social support. According to Pottie and colleagues (2009), parents of children with ASD have been found to experience significantly higher levels of parenting stress and psychological distress than those parents of typically developing children or those parents of children with other disabilities, with most of the stress resulting from the disruptive childhood behaviors associated with ASD. One variable that has been extensively studied as a possible predictor of parental stress is the severity of the child's symptoms (Benson & Karlof, 2009). As noted previously, children with ASD exhibit a wide array of problematic symptoms and behaviors that can adversely affect parent and family well-being thereby leading to increased stress (Benson & Karlof, 2009). There is also reason to believe that stress can be related to sustained caregiving and disruption of relationships, finances, work, and family life (Benson & Karlof, 2009).

Problems associated with a child having an ASD can be especially difficult for mothers, who are often the primary caregiver (Eisenhower et al., 2005). According to Tobing and Glenwick (2006), several studies have indicated that mothers of children with ASDs are likely to report more depressive symptoms and adjustment problems than many other parents of children with disabilities. According to Hoffman et al (2009), mothers were most adversely

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affected by the negative impact associated with their child's ASD. Hastings and colleagues (2005) found that mothers of children with an ASD suffered from more depressive symptoms than fathers and that child behavior problems strongly positively predicted maternal stress. Mothers' lack of sleep was positively related to the child's autistic severity leading to reports of maternal stress (Hoffman et al, 2009). Finally, Dale and colleagues (2006) found that stress resulted from self-blame for their child's disorder.

Social support describes different aspects of an individual's social circumstance that may augment physical and psychological well-being (Cohen et al., 2000). Pottie and colleagues (2009) found that daily received emotional, and instrumental social support was associated with parental mood changes and that this support only buffered the effects of parenting stress. It was also found that support services often played a significant role in helping parents cope with challenging behaviors and developmental delays (Pottie et al., 2009). According to Altieri and von Kluge (2009), social support is especially important for mothers raising a child with an ASD in which mothers who experience more social support report less stress and depression. Hare and colleagues (2004) found that there was a reliance on formal support rather than family or informal support and that parent groups and national support groups were not well utilized.

Limitations of this integrative review include some threats to validity in integrative reviews that differ from other research methodologies. For example, the research studies presented in this paper come from a number of different journals that have varying criteria for publication. In addition, there is potential for incomplete reporting by the primary researcher of the selected studies used for this review.

The results of this review have revealed three prominent themes. However, it was troubling that the results of this integrative review did not find any studies on the lived

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experience of parents who have a child or children with an ASD. It would be of interest to learn about the total experience of parents who have a child with an ASD so that the child and family's social, medical and educational needs can be better met for this vulnerable population.

According to Clarke Moustakas, the nature of the lived experience allows the individual to focus on seeing, listening, touching, and thinking on what that experience is in its essences (Moustakas, 1994). The researcher can examine how it is that that experience is what it is, under what conditions it occurs, from what frame of reference, and what its possible meanings are (Moustakas, 1994). By turning to the lived experience, the researcher can describe in detail the whole account of an issue, problem, situation, or experience, using qualities and properties from specific contexts or perspectives, so that the experience takes on a vivid or essential meaning, a clear picture of what is (Moustakas, 1994).

More qualitative research is needed to elicit the meaning of the relational and contextual factors affecting parents who have a child with Autism Spectrum Disorder. Qualitative approaches, including open-ended interviews, would allow for interaction between the participants and the researcher and would allow the investigator to understand the meaning of the totality of the experience of parents having a child with an ASD, a phenomenon still requiring further research.

Chapter Four

VCU IRB FULL and EXPEDITED STUDY INITIAL REVIEW SUBMISSION FORM

IRB NUMBER: _____

DO NOT DELETE SECTIONS OF THIS FORM

SECTION 1: PRINCIPAL INVESTIGATOR AND OTHER VCU LEAD PROJECT PERSONNEL

1. PRINCIPAL INVESTIGATOR: LIST NAME AS IT EXISTS IN THE HUMAN RESOURCE SYSTEM (HRS)

NOTE: See guidance on who can serve as PI at [HTTP://WWW.RESEARCH.VCU.EDU/IRB/WPP/FLASH/IX-1.HTM](http://www.research.vcu.edu/irb/wpp/flash/ix-1.htm)
(effective date 4-15-06)

Name (Last, First, MI): Pickler, Rita H

PI Title and Degrees: Professor, PhD

VCU Department: Family and Community Health Nursing

VCU Box # (must provide 6-
digit #): 980567

Phone/Pager/Fax #'s: 804-828-0721

VCUEmail: RPICKLER@VCU.EDU

2. VCU LEAD PROJECT PERSONNEL: LIST NAMES AS THEY EXIST IN THE HUMAN RESOURCE SYSTEM (HRS)

If the PI cannot be contacted, these persons may be contacted by the IRB. Within the Research Synopsis, you will have the opportunity to list all key project personnel.

SUB/CO-INVESTIGATOR:

Name (Last, First, MI), Degrees: _____

Department: _____

Phone/Pager/Fax #'s: _____

Email: _____

MEDICALLY RESPONSIBLE INVESTIGATOR (if applicable):

Name (Last, First, MI), Degrees: _____

Department: _____

Phone/Pager/Fax #'s: _____

Email: _____

RESEARCH COORDINATOR (if applicable):

Name (Last, First, MI), Degrees: _____

Department: _____

Phone/Pager/Fax #'s: _____

Email: _____

TRAINEE (Postdoctoral Scholar, Fellow or Resident) (if applicable):

Name (Last, First, MI), Degrees: _____

Department: _____

Phone/Pager/Fax #'s: _____

Email: _____

STUDENT (if applicable):

Name (Last, First, MI), Degrees: Strunk, Julie; MSN

Department: Nursing

Phone/Pager/Fax #'s: 540-564-1728

Email: STRUNKJA@VCU.EDU

SECTION 2: TYPE OF SUBMISSION

Please check all categories that apply to the study being submitted for IRB review.

RESEARCH PROJECT

FDA REGULATED RESEARCH*

* FDA regulated research includes:

- a) any research involving a drug or biologic intended for human use (other than the use of an approved drug in the course of medical practice);
- b) any research designed to test the safety and effectiveness of a device; or
- c) research involving ANY FDA regulated product where the intent is to submit data to the FDA in support of a research or marketing application. Regulated products include foods & dietary supplements, infant formulas, food & color additives, and electronic products.

CLINICAL TRIAL

See definition of clinical trial at <http://www.clinicaltrials.vcu.edu/glossary.html#C>.

HUMANITARIAN USE DEVICE

See guidance at <http://www.research.vcu.edu/irb/wpp/flash/XVI-2.htm>

TREATMENT USE OF INVESTIGATIONAL DRUG/DEVICE

See guidance at <http://www.research.vcu.edu/irb/wpp/flash/XVI-5.htm>

SECTION 3: TYPE OF REVIEW

REVIEW TYPE REQUESTED (check one):

FULL BOARD REVIEW

NOTE: Industry-sponsored research **MUST** be submitted to Western IRB (WIRB) for review. See instructions available at <http://www.research.vcu.edu/forms/wirb.htm>

EXPEDITED REVIEW

* **EXPEDITED CATEGORIES:** 6, 7

* Identify the expedited category or categories in which your research falls (See Expedited Review Guidance at <http://www.research.vcu.edu/irb/reviewtypes.htm>)

NOTE: For projects requesting exempt review determination, use the exempt review submission form, available at <http://www.research.vcu.edu/forms/vcuirb.htm>.

SECTION 4: PROJECT INFORMATION

1. PROJECT TYPE (check one):

- BIOMEDICAL** Research involving medical interventions and/or FDA-regulated products
- SOCIAL-BEHAVIORAL (check one):** Social or behavioral research that does **NOT** involve medical interventions or FDA-regulated products
- SOCIAL-BEHAVIORAL QUALITATIVE**
- SOCIAL-BEHAVIORAL QUANTITATIVE**
- SOCIAL-BEHAVIORAL QUALITATIVE & QUANTITATIVE**

2. TITLE OF PROTOCOL SUBMISSION:

The Lived Experience of Parents who have a Child with Autism Spectrum Disorder

3. Are there any IRB-APPROVED PROTOCOLS ASSOCIATED with this submission? YES NO

If YES, please list the associated VCU IRB Protocol #'s:

Note: If this submission is associated with other new projects submitted to the IRB but not yet approved), please attach a cover memo to your submission noting related projects.

4. Is this a TRAINEE OR STUDENT PROJECT in which activities will be carried out by that individual under your supervision? YES NO

SECTION 5: SPONSOR DATA

1. Does the research project involve a DIRECT FEDERAL AWARD made to VCU (or a research funding proposal for such)? YES NO

2. Have you submitted a related research funding proposal(s) to the VCU Office of Sponsored Programs (OSP)? YES NO

If YES, you must provide the **PT/PD #** for each related proposal (**regardless of the funding source**):

(1) (2) (3)

NOTE: Federal regulations require IRB approval of **NEW**, **RESUBMISSION**, or **COMPETING CONTINUATION** FEDERAL RESEARCH FUNDING PROPOSALS. If there is a new, resubmission, or competing continuation VCU federal research funding proposal associated with this research project, you must include a copy of your **ENTIRE** proposal (exclusive of appendices) and OSP Internal Approval Form with this submission. Failure to do so may delay your research award start date. Other sponsors also may require IRB approval of research proposals. It is the investigator's responsibility to determine whether this review is needed. If the sponsor does not require IRB approval of research proposals, **DO NOT** submit them to the IRB for review. If you have questions about whether your sponsor requires IRB approval of your research funding proposal, please contact OSP.

SECTION 6: STATEMENTS OF COMPLIANCE

PRINCIPAL INVESTIGATOR STATEMENT OF COMPLIANCE:

I understand and accept responsibility for ensuring the safety and welfare of all human subjects who participate in the proposed research project. I certify that all key project personnel, including myself, sub/co-investigators, research coordinators, trainees, and students have completed the VCU required training on human subjects protection. I agree to a continuing exchange of information with the VCU IRB including the requirements to (i) obtain IRB approval before making non-emergency changes/revisions to the project, except where necessary to eliminate apparent immediate hazards to subjects or others, (ii) provide progress reports to the VCU IRB at their request (and at least annually), and (iii) report promptly to the IRB all unanticipated problems and serious adverse events involving risk to human subjects (in accordance with required reporting timelines by the IRB).

SIGNATURE OF INVESTIGATOR: _____

DATE OF SIGNATURE: _____

TRAINEE OR STUDENT INVESTIGATOR STATEMENT OF COMPLIANCE (IF APPLICABLE):

This is a student or trainee project, which will potentially be presented outside the classroom and/or published. I understand that I may not proceed with the research without first receiving a formal written letter of approval from the VCU IRB. I certify that I have completed the VCU required training on human subjects protection.

SIGNATURE OF TRAINEE OR STUDENT:

DATE OF SIGNATURE:

DEPARTMENT/DIVISION CHAIRPERSON OR DEAN STATEMENT OF COMPLIANCE*see NOTE:

I certify that the research project referenced in this document (check one of the following):

Has been subjected to scrutiny within a VCU Committee (i.e., Massey Cancer Center Protocol Review, Clinical Research Center [CRC]) or sponsor study group (i.e., NIH or other agency with appropriate scientific expertise) and found to be scientifically acceptable.

Has been subjected to scrutiny by my designee or me according to criteria that include the following, as applicable: appropriate power and sample size, currency of literature review, and relevance of hypothesis or research question and found to be scientifically acceptable.

PRINT NAME, DEGREES, TITLE OF Debra Lyon, PhD, Chair, FCHN

DEPARTMENT/DIVISION CHAIRPERSON OR DEAN:

SIGNATURE OF DEPARTMENT/ DIVISION

CHAIRPERSON OR DEAN:

DATE OF

SIGNATURE:

***NOTE:** Department/Division Chairperson cannot sign if he/she is a co-investigator on the project. In these instances, a Dean's signature is required. If a designee is signing the Statement of Compliance, his/her name, degrees, and title should be listed.

SECTION 7: PROJECT DETAIL

ANSWER ALL OF THE FOLLOWING QUESTIONS (by marking the appropriate box to the right):

1. Will DRUG(S), BIOLOGIC(S), OR DEVICE(S) be utilized for this project? YES NO*
If NO, skip to Question 6.

2. Will DRUG(S) be administered in this project? If YES, supply the following information (attach a separate sheet if necessary): YES NO

DRUG NAME(S):

2-A. If drug is INVESTIGATIONAL or involves an IND, please complete the following:

IND #: _____ **HELD BY (check one):** SPONSOR INVESTIGATOR N/A

- If IND is held by the SPONSOR, provide copy of the INVESTIGATOR'S BROCHURE and the SPONSOR'S PROTOCOL
- If IND is held by the INVESTIGATOR, provide copy of the IND APPLICATION submitted to the FDA and safety information
- Attach copy of FDA FORM 1572

3. Will BIOLOGIC AGENTS be used in this project? If YES, supply the following information: YES NO

BIOLOGIC NAME(S):

4. Will the VCU/VCUHS INVESTIGATIONAL DRUG SERVICE PHARMACY (IDS) be utilized (required for all inpatient projects)? YES NO* N/A**

*If NO, you must submit a descriptive plan regarding appropriate drug storage and dispensing for an investigational drugs or biologic agents/drugs used in the research to the Investigational Drug Service (IDS) Pharmacy. Guidance and the form for describing the management plan is located at <http://www.investigationaldrugs.vcu.edu>. Submit the form to the IDS. Upon IDS's receipt of the plan, an email response containing the plan is generated. Include the IDS confirmation or receipt with this submission. For assistance, please call the Investigational Drug Pharmacy at 828-7901.

**Submitting a plan to the IDS is not required if: 1) no drugs are used in the study, 2) the drug used in the study is FDA-

approved, considered standard of care and is a patient-charge item, 3) off-label use of such a drug is not being studied and 4) there is no protocol requirement for specific management of the drug.

5. Are you evaluating MARKETED MEDICAL DEVICE(S) (including 510k devices) in this project? If YES, supply the following information: YES NO

DEVICE NAME(S): _____

NAME OF MANUFACTURER: _____

NOTE: In addition, provide any supporting documentation regarding LEVEL OF RISK (SIGNIFICANT vs. NON-SIGNIFICANT RISK)

6. Are you evaluating INVESTIGATIONAL MEDICAL DEVICE(S) or a NEW USE FOR MARKETED MEDICAL DEVICE(S) in this project? If YES, supply the following information: YES NO

DEVICE NAME(S): _____

NAME OF MANUFACTURER: _____

IDE #: _____ **HELD BY (check one):** SPONSOR INVESTIGATOR N/A

• If IDE is held by the SPONSOR, provide a copy of the INVESTIGATOR'S BROCHURE and the SPONSOR'S PROTOCOL

• If IDE is held by the INVESTIGATOR, provide a copy of the IDE APPLICATION submitted to the FDA

NOTE: In addition, provide any supporting documentation regarding LEVEL OF RISK (SIGNIFICANT vs. NON-SIGNIFICANT risk)

7-A. Does this project involve the use of any procedure(s) that will expose the research subject to IONIZING RADIATION?

YES (Proceed to 7-B)

NO (Proceed to Question 8)

7-B. If all of these procedures are for the direct clinical benefit of the research subject/patient, check YES. If any of these procedures are of research interest only and will not affect the clinical management of the research subject, check NO.

YES (no further information required)

NO (Proceed to 7-C)

7-C. RADIATION SAFETY COMMITTEE (RSC) approval is required if you answered NO to item 7-B. Do you have RSC approval for this project?

YES (Attach copy of RSC Approval Letter)

NO (Contact the Radiation Safety Section at 828-9131 for approval information)

NOTE: See also <http://www.vcu.edu/oehs/radiation/humanuseguide.pdf>

8-A. Does this project involve the use of RECOMBINANT DNA, BIO-HAZARDOUS SUBSTANCES including pathogenic or potentially pathogenic viruses and bacteria (e.g., Adenovirus, HIV, Hepatitis B), CARCINOGENS OR ACUTE CARCINOGENS, MUTAGENS, TERATOGENS, ACUTE TOXINS, OR SELECT AGENT MATERIALS?

YES (Proceed to 8-B)

NO (Proceed to Question 9)

8-B. INSTITUTIONAL BIOSAFETY COMMITTEE (IBC) approval is required if you answered YES to this question. Do you have IBC approval for this project?

YES (Attach copy of IBC Approval Letter)

NO (Contact CHEMICAL AND BIOLOGICAL SAFETY OFFICE at 828-4866 for approval information)

NOTE: See also <http://www.vcu.edu/oehs/chemical/>

9. Does this project involve GENE THERAPY? YES NO

10-A. Does this study involve cancer patients, their families, or their health care providers? YES * NO

10-B. Is this a Cancer Prevention Study? YES * NO

* If YES TO 10-A OR 10-B, the research project must be reviewed and approved by the MASSEY CANCER CENTER PROTOCOL REVIEW AND MONITORING SYSTEM before IRB Review, and a copy of the approval letter provided. For information, see <http://www.massey.vcu.edu/research/?pid=2013> or call the PRMS Coordinator at 628-1924.

11. Will this project be conducted in the CLINICAL RESEARCH CENTER (CRC)? YES * NO

* If YES, please review information for investigators available at <http://www.vcuhealth.org/crc/>

12. Is your project: (1) involving human subject activities conducted by Navy and Marine Corps personnel; (2) involving naval military personnel and Department of Navy (DoN) employees as research subjects; (3) supported by naval activities through any agreement (e.g., contract, grant cooperative agreement, development agreement [CRADSs], or other arrangement), regardless of the source of funding, funding appropriation, nature of support, performance site, or security classification; or (4) using DoN property, facilities or assets? YES * NO

* If YES, you must ensure that your project meets the additional Department of Defense (DoD)-Department of the Navy (DoN) requirements for human subject protection. Guidance on additional requirements can be found at [\[http://www.research.vcu.edu/irb/wpp/flash/XVII-12.htm\]](http://www.research.vcu.edu/irb/wpp/flash/XVII-12.htm)

13. Will this project be conducted in a VCUHS patient care area or involve VCUHS patients? YES NO

If yes, review the CONDUCT OF CLINICAL RESEARCH IN VCU HEALTH SYSTEM PATIENT CARE AREAS policy on this page: <http://www.research.vcu.edu/irb/guidance.htm>.

14. HIPAA Regulatory Compliance

14-A. Check all that apply to the data you plan to collect or store. Data will be: NONE

<input type="checkbox"/> Used to make health care decisions	<input type="checkbox"/> Collected from a data set that is under the VCU ACE
<input type="checkbox"/> Added to a data set under the VCU ACE	<input type="checkbox"/> Derived or extracted from the medical record
<input type="checkbox"/> Created and stored in a data set under the VCU ACE	

Note: VCU ACE is the VCU Affiliated Covered Entity. Review the entities included in the VCU ACE here: http://www.vcu.edu/hipaa/VCU_ACE.html.

14-B. Please check if you will collect any of these identifiers about past or current patients of the VCUHS: NONE

<input type="checkbox"/> Names	<input type="checkbox"/> SSNs	<input type="checkbox"/> Dates	<input type="checkbox"/> Device identifiers	<input type="checkbox"/> Phone numbers
<input type="checkbox"/> MRN	<input type="checkbox"/> Web URLs	<input type="checkbox"/> Email addresses	<input type="checkbox"/> IP addresses	<input type="checkbox"/> Account numbers
<input type="checkbox"/> Health plan numbers	<input type="checkbox"/> Photos or comparable images	<input type="checkbox"/> Biometric identifiers	<input type="checkbox"/> License/Certificate numbers	<input type="checkbox"/> Vehicle ID numbers
<input type="checkbox"/> Other unique identifier				

If you checked any of the items in **BOTH** 14-A AND 14-B, this study is using Protected Health Information (PHI) and HIPAA regulations apply. **You are required to submit a “HIPAA Research Compliance Form” to the Department of Compliance Services.** (Form does not need to be included in IRB packet) Access the form here: http://www.vcu.edu/hipaa/Document_Links/ResearchComplianceFormIRBSupplement.doc.

15. Does this project involve the creation of or contribution to a Research Registry? YES* NO**
(Registries are sometimes called repositories, data sets, data banks, tissue or specimen banks)

* If YES, you must follow guidance at <http://www.research.vcu.edu/irb/wpp/flash/XVII-4.htm> and answer 15-A and 15-B.

**If NO, skip to Question 16

15-A. Will the registry be maintained at VCU? YES NO

15-B. Does the registry include one of the HIPAA elements listed in 14-B? YES NO

16. Do you plan to involve NON-VCU INSTITUTIONS (i.e., institutions [or employees or agents of the institutions] that are not under the authority of VCU or VCU Health Systems and are located within the United States or a United States territory) in your research project? YES * NO
* If YES, you must follow guidance at <http://www.research.vcu.edu/irb/wpp/flash/XVII-6.htm>

17. Do you plan to involve FOREIGN RESEARCH SITES (i.e., institution or non-institutional setting)? YES * NO
* If YES, you must follow guidance at <http://www.research.vcu.edu/irb/wpp/flash/XVII-11.htm>

18. Do you plan to involve INDEPENDENT INVESTIGATORS (i.e., individuals who are not representatives of VCU or any other institution or facility) in your research project? YES * NO
* If YES, you must follow guidance at <http://www.research.vcu.edu/irb/wpp/flash/XVII-15.htm>

19. Does this project involve GENETIC TESTING, that is, testing human tissue samples for heritable characteristics or storing human tissue samples for possible future such testing? YES * NO
* If YES, you must follow guidance at <http://www.research.vcu.edu/irb/wpp/flash/XVII-5.htm>

SECTION 8: RESEARCH SUBJECT INFORMATION

VULNERABLE SUBJECTS:

Consider your criteria for inclusion or exclusion of any subpopulation, review the following information, and identify research categories (as appropriate).

BOX 1: CHILDREN: If you plan to allow for the inclusion of data on subjects who are children, you must indicate the inclusion of their data and identify a research category or categories below.

NOTE: In Virginia, children are those under the age of 18 and not emancipated.

Do you plan to allow for the inclusion of data on subjects who are children?

YES * NO

* If YES, identify the research category or categories below.

- Research not involving greater than minimal risk (45 CFR 46.404) – [**NOTE:** see definition of minimal risk below]
- Research involving greater than minimal risk but presenting the prospect of direct benefit to individual subjects (45.CFR 46.405)
- Research involving greater than minimal risk and no prospect of direct benefit to individual subjects, but likely to yield generalizable knowledge about the subject's disorder or condition. (45.CFR 46.406)¹
- Research not otherwise approvable which presents an opportunity to understand, prevent, or alleviate a serious problem affecting the health or welfare of children. (45.CFR 46.407)¹

MINIMAL RISK means that the probability and magnitude of harm or discomfort anticipated in the research are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests.

¹ Categories 406 and 407 **REQUIRE BOTH** parents to provide permission for the child's participation unless one is deceased, unknown, incompetent, or only one parent has legal responsibility for care and custody. The IRB may determine that permission of both parents is required for categories 404 or 405.

NOTE: If you plan to allow for the inclusion of data on subjects who are children, you must include the VCU IRB CHILDREN-SUBJECT FORM with your submission. The form is available at <http://www.research.vcu.edu/forms/vcuirb.htm>

BOX 2: PREGNANT WOMEN, HUMAN FETUSES, AND NEONATES: If you plan to allow for the inclusion of data on subjects who are pregnant women, human fetuses, or neonates as subjects, you must indicate inclusion of their data and identify a research category or categories below.

Do you plan to allow for the inclusion of data on subjects who are PREGNANT WOMEN, HUMAN FETUSES, or NEONATES as subjects?

YES * NO

* If YES, identify the research category or categories below.

- Research involving pregnant women or fetuses [PW-HF-N (45.CFR46.204)]
- Research involving neonates of uncertain viability and nonviable neonates [PW-HF-N (45.CFR46.205(a)(b)(c))]
- Research involving neonates of certain viability [PW-HF-N (45.CFR46.205(d))]
- Research involving after delivery, the placenta, the dead fetus or fetal material[PW-HF-N (45.CFR46.206)]
- Research not otherwise approvable, which presents an opportunity to understand, prevent, or alleviate a serious problem affecting the health or welfare of pregnant women, fetuses, or neonates [PW-HF-N (45.CFR.46.207)]

NOTE: If you plan to allow for the inclusion of data on subjects who are pregnant women, fetuses, or neonates you must include the VCU IRB PREGNANT WOMEN, FETUSES, NEONATES-SUBJECT FORM with your submission. The form is available at <http://www.research.vcu.edu/forms/vcuirb.htm>

BOX 3: PRISONERS: If you plan to allow for the inclusion of data on subjects who are, or may become, a prisoner, you must indicate that you plan to allow for inclusion of their data and identify a research category below. **NOTE: If an enrolled research subject becomes incarcerated (or otherwise meets the definition of prisoner) during the course of an IRB approved project, the PI must immediately notify the IRB and amend the protocol to allow for the inclusion of prisoners and the continuation of that subject.** If this should occur, you must follow the VCU IRB PRISONER-SUBJECT GUIDANCE and include the VCU IRB PRISONER-SUBJECT FORM with your submission to the IRB. The guidance and form are available at <http://www.research.vcu.edu/forms/vcuirb.htm>

Do you plan to allow for the inclusion of data on subjects who are, or may become a PRISONER? YES * NO

* If YES, identify the research category below.

- Research involving study of the possible causes, effects, and processes of incarceration, and of criminal behavior, provided that the project presents no more than minimal risk and no more than inconvenience to the subjects (45.CFR 46.306(a)(2)(i)) – [NOTE: see definition of minimal risk below]
- Research involving study of prisons as institutional structures or of prisoners as incarcerated persons, provided that the project presents no more than minimal risk and no more than inconvenience to the subjects (45.CFR 46.306(a)(2)(ii)) – [NOTE: see definition of minimal risk below]
- Research on conditions particularly affecting prisoners as a class (for example, vaccine trials and other research on hepatitis which is much more prevalent in prisons than elsewhere; and research on social and psychological problems such as alcoholism, drug addiction, and sexual assaults) provided that the project may proceed only after the Secretary (through OHRP) has consulted with appropriate experts including experts in penology, medicine, and ethics, and published notice, in the Federal Register, of his intent to approve such research (45.CFR 46.306(a)(2)(iii))
- Research on practices, both innovative and accepted, which have the intent and reasonable probability of improving the health or well-being of the subject. In cases in which those studies require the assignment of prisoners in a manner consistent with projects approved by the IRB to control groups which may not benefit from the research, the project may proceed only after the Secretary (through OHRP) has consulted with appropriate experts including experts in penology, medicine, and ethics, and published notice, in the Federal Register, of his intent to approve such research (45.CFR 46.306(a)(2)(iv))
- Research defined as public health research that focuses on a particular condition or disease in order to (i) describe its prevalence or incidence by identifying all cases, including prisoner cases, or (ii) study potential risk factor associations, where the human subjects may include prisoners in the project population but not exclusively as a target group, provided that the project presents no more than minimal risk and no more than inconvenience to the subjects (Epidemiological Waiver Request)

MINIMAL RISK AS IT PERTAINS TO THE PRISONER POPULATION means that the probability and magnitude of physical or psychological harm that is normally encountered in the daily lives or in the routine medical, dental, or psychological examination of healthy, non-incarcerated persons.

NOTE: If you plan to allow for the inclusion of data on subjects who are, or may become, prisoners, you must follow the VCU IRB PRISONER-SUBJECT GUIDANCE and include the VCU IRB PRISONER-SUBJECT FORM with your submission. The guidance and form are available at <http://www.research.vcu.edu/forms/vcuirb.htm>

SUBJECT ENROLLMENT PLAN:

Anticipated # OF SUBJECTS (if this is a multi-center project, list only subjects under this IRB approval): 10

Is this a **MULTI-CENTER PROJECT**? YES NO

If YES, please provide:

(1) # OF SITES:

(2) # OF SUBJECTS ACROSS ALL SITES:

CONSENT DOCUMENTATION: (Mark the type of consent process/documentation planned):

- STANDARD CONSENT FORM:** A copy of the proposed consent form(s) is attached to this submission.
- CONSENT FORM FOR PRISONER SUBJECTS:** A copy of the proposed consent form for prisoners is attached to this submission.
- WAIVER OF SOME OR ALL ELEMENTS OF CONSENT OR PARENTAL PERMISSION:** **NOTE:** Waiver is not allowed for FDA-regulated research unless it meets FDA requirements for Waiver of Consent for Emergency Research (see below). A request is being made to waive the requirement to obtain prospective informed consent from subjects or permission from parents. Your research synopsis should explain why: (1) the research involves no more than minimal risk to the subjects, (2) the waiver or alteration will not adversely affect the rights and welfare of the subjects, (3) the research could not practicably be carried out without the waiver or alteration; **AND** (4) whether or not subjects will be debriefed after their participation. Guidance is available at <http://www.research.vcu.edu/irb/wpp/flash/XI-1.htm>.
- WAIVER OF DOCUMENTATION OF CONSENT, PARENTAL PERMISSION:**
A request is being made to waive documentation of consent. The IRB may waive this requirement if it finds either: (1) that the only record linking the subject and the research would be the consent document and the principal risk would be potential harm resulting from a breach of confidentiality. Subjects will be asked whether they want documentation linking them with the research, and each subject's wishes will govern; or (2) that the research presents no more than minimal risk of harm to subjects and involves no procedures for which written consent is normally required outside of the research context. Your research synopsis should include a justification for waiver based on one of these two elements and include a description of the information that will be provided to participants. If you are proposing to use a verbal consent statement, the proposed consent script should be attached to this submission. Guidance is available at <http://www.research.vcu.edu/irb/wpp/flash/XI-2.htm>
- ASSENT FORM:** A copy of the assent form for children or decisionally-impaired persons is attached to this submission. Guidance is available at <http://www.research.vcu.edu/irb/wpp/flash/XV-2.htm>. and <http://www.research.vcu.edu/irb/wpp/flash/XVII-7.htm>.
- WAIVER OF ASSENT:** A request is being made to waive the requirement to obtain prospective assent from children age 7 or higher, or decisionally-impaired persons. Your research synopsis should explain (1) why some or all of the individuals age 7 or higher, or decisionally-impaired will not be capable of providing assent based on their developmental status or impact of illness; (2) the research holds out a prospect of direct benefit not available outside of the research; **AND/OR** (3) [a] the research involves no more than minimal risk to the subjects, [b] the waiver or alteration will not adversely affect the rights and welfare of the subjects, [c] the research could not practicably be carried out without the waiver or alteration; **AND** [d] whether or not subjects will be debriefed after their participation. Guidance is available at <http://www.research.vcu.edu/irb/wpp/flash/XV-2.htm>.
- Waiver of Consent for Emergency Research:** Guidance is available at <http://www.research.vcu.edu/irb/wpp/flash/XVII-16.htm>.

SECTION 9: VCU RESEARCH PLAN

You must use the VCU Research Plan Template that can be found at <http://www.research.vcu.edu/forms/vcuirb.htm>, Use of this template is required to provide your VCU Research Plan to the IRB. Your responses should be written in terms for the non-scientist to understand. If a detailed research protocol (e.g., sponsor's protocol) exists, you may reference that protocol. **NOTE: If that protocol does not address all of the issues outlined in each Section Heading, you must address the remaining issues in this Plan. It is NOT acceptable to reference a research funding proposal.**

SECTION 10: SUBMISSION CHECKLIST

The following elements are reminders of steps and documentation that must be included with your submission packet.
NOTE: If required documents are missing and multi-page documents are not individually stapled or clipped, your review may be delayed.

This checklist must be included as the last page of the IRB INITIAL REVIEW SUBMISSION FORM
If not applicable, indicate “N/A.”

- 1. VCU IRB INITIAL REVIEW SUBMISSION FORM**
- 2. VCU RESEARCH PLAN**
Required with ALL submissions and MUST follow the template and include version number or date, and page numbers [see SECTION 9 of this form]. Review of your protocol will be delayed if the template is not followed.
NOTE: A research funding proposal cannot substitute for the VCU Research Plan
- NA **3. MEASURES (e.g., surveys, questionnaires, instruments, appendices)**
Measures MUST include title, version number or date, and page numbers
- NA **4. SPONSOR’S PROTOCOL**
If a sponsor’s protocol exists, it must be submitted with the VCU Research Synopsis.
NOTE: A research funding proposal is not considered a Sponsor’s protocol
- 5. ADVERTISEMENTS/SUBJECT RECRUITMENT MATERIALS**
If approval is sought for advertisement/subject recruitment materials at this time. Materials MUST include version number or date
- 6. INFORMED CONSENT/ASSENT DOCUMENT(S)**
Informed consent document(s) should follow a version of the VCU IRB CONSENT TEMPLATE and MUST include version number or date, and page numbers
- NA **7. VCU IRB CHILDREN-SUBJECT FORM**
- NA **8. VCU IRB PREGNANT WOMEN, FETUSES, AND NEONATES-SUBJECT FORM**
- NA **9. VCU IRB PRISONER-SUBJECT FORM**
- NA **10. FDA FORM 1572**
If investigational drugs are involved in the research
- NA **11. INVESTIGATIONAL DRUG PHARMACY PLAN**
If a drug or biologic agent/drug will be used in the research and IDS will not be used, confirmation from IDS that a plan has been received is required with this submission [see SECTION 7(4) of this form]
- NA **12. IND OR IDE APPLICATION**
If a drug or device is used in the project and IND or IDE is held by the investigator [see SECTION 7(2) or 7(5) of this form]
- NA **13. INVESTIGATOR’S BROCHURE**
If a drug or device is used in the project and the IND or IDE is held by the sponsor [see SECTION 7(2) or 7(5) of this form]
- NA **14. DOCUMENTATION REGARDING LEVEL OF RISK (when evaluating a device)**
If an investigational medical device or a new use for marketed medical device is being evaluated [see SECTION 7(5) or 7(6) of this form]

- NA **15. RADIATION SAFETY COMMITTEE APPROVAL** If required [see SECTION 7(7) of this form]
- NA **16. INSTITUTIONAL BIOSAFETY COMMITTEE REVIEW** If required [see SECTION 7(8) of this form]
- NA **17. MASSEY CANCER CENTER PROTOCOL REVIEW AND MONITORING SYSTEM APPROVAL**
If required, [see SECTION 7(10) of this form]
- 18. CONFLICT OF INTEREST DISCLOSURE STATEMENT**
This form and explanatory supplement (if applicable) is required for the PI and all others who have responsibility for the design, conduct, or reporting of the research.
- NA **19. RESEARCH FUNDING PROPOSAL**
If required [see SECTION 5 of this form] The enter proposal (exclusive of appendices) and VCU Office of Sponsored Programs (OSP) Internal Approval Form must be included.
- 20. PRINCIPAL INVESTIGATOR CV (not to exceed 5-6 pages) or a BIOSKETCH (2-3 pages)**
If submitting a biosketch, the NIH biosketch form (398) must be used. The biosketch form is available at <http://grants.nih.gov/grants/funding/phs398/biosketch.pdf>. Additional instructions are available at <http://grants1.nih.gov/grants/funding/phs398/phs398.html>.
- 21. CV OF DOCTORAL STUDENT, POSTDOCTORAL SCHOLAR, FELLOW, OR RESIDENT (not to exceed 5-6 pages) or a BIOSKETCH (2-3 pages)**
If submitting a biosketch, the NIH biosketch form (398) must be used. The biosketch form is available at <http://grants.nih.gov/grants/funding/phs398/biosketch.pdf>. Additional instructions are available at <http://grants1.nih.gov/grants/funding/phs398/phs398.html>.
- NA **22. MEDICALLY RESPONSIBLE INVESTIGATOR CV (not to exceed 5-6 pages) or a BIOSKETCH (2-3 pages)**
If submitting a biosketch, the NIH biosketch form (398) must be used. The biosketch form is available at <http://grants.nih.gov/grants/funding/phs398/biosketch.pdf>. Additional instructions are available at <http://grants1.nih.gov/grants/funding/phs398/phs398.html>.
- 23. OTHER:** _____

In addition, please ensure the following:

- All key project personnel, including the principal investigator, sub/co-investigators, project coordinators, and students have completed **VCU REQUIRED TRAINING ON HUMAN SUBJECTS PROTECTION**. The exam can be accessed from the following website <http://www.research.vcu.edu/irb/education.htm>
- Principal Investigator, Trainee or Student (if applicable) and Department/Division Chairperson or Dean have **SIGNED THE APPROPRIATE STATEMENTS OF COMPLIANCE** [see SECTION 6 of this form]
- The **REVIEW TYPE REQUESTED** [see SECTION 3 of this form] has been checked

NUMBER OF COPIES REQUIRED

NOTE: If required documents are missing, multi-page documents are not individually stapled or clipped, or the documents are not provided in the order noted below, your review may be delayed.

I. If review type requested is **EXPEDITED**, submit **(4) COLLATED SETS** containing the following documents in the order noted.

- 1) VCU IRB Initial Review Submission Form
- 2) VCU Research Plan
- 3) Sponsor's Protocol (if applicable)
- 4) Advertisements/Subject Recruitment Materials (if applicable)
- 5) Informed Consent/Assent Documents(s) (if applicable) (**NOTE:** If this is a DHHS protocol, you **MUST** include the DHHS-approved consent/assent documents)
- 6) VCU IRB Children-Subject Form (if applicable)
- 7) VCU IRB Pregnant Women, Fetuses, Neonates-Subject Form (if applicable)
- 8) VCU IRB Prisoner-Subject Form (if applicable)
- 9) Confirmation of receipt of management plan from Investigational Drug Pharmacy (if applicable)
- 10) FDA Form 1572 (if applicable)
- 11) IND or IDE Application (if applicable)
- 12) Investigator's Brochure (if applicable)
- 13) Radiation Safety Committee Approval Letter (if applicable)
- 14) Massey Cancer Center Protocol Review and Monitoring System Approval Letter (if applicable)
- 15) Conflict of Interest Disclosure Statement (s) and supplement(s) if applicable
- 16) Research Funding Proposal (if applicable)
- 17) Principal Investigator CV or Biosketch
- 18) CV of Doctoral Student, Postdoctoral Scholar, Fellow, or Resident (if applicable)

II. If review type requested is **FULL BOARD**, submit **(25) SETS IN TOTAL** as follows.

A) Submit **(25) COLLATED SETS** containing the following documents in the order noted:

- 1) VCU IRB Initial Review Submission Form
- 2) VCU Research Plan
- 3) Sponsor's Protocol (if applicable)
- 4) Advertisements/Subject Recruitment Materials (if applicable)
- 5) Informed Consent/Assent Document(s) (if applicable) (**NOTE:** If this is a DHHS protocol, you **MUST** include the DHHS-approved consent/assent documents)
- 6) VCU IRB Children-Subject Form (if applicable)
- 7) VCU IRB Pregnant Women, Fetuses, Neonates-Subject Form (if applicable)
- 8) VCU IRB Prisoner-Subject Form (if applicable)
- 9) Conflict of Interest Disclosure Statement. Submit 20 COPIES of the Conflict of Interest Disclosure Statement AND Disclosure Supplement Form(s) IF any of the investigators answered YES to one of the questions. Otherwise, submit only 4 COPIES.

AND

B) In addition, **(4) OF THE 25 COLLATED SETS** must containing the following documents:

- 1) Principal Investigator CV or Biosketch
- 2) FDA Form 1572 (if applicable)
- 3) IND or IDE Application (if applicable)
- 4) Investigator's Brochure (if applicable)
- 5) Documentation of Level of Risk (if applicable)
- 6) Radiation Safety Committee Approval Letter (if applicable)
- 7) Massey Cancer Center Protocol Review and Monitoring System Approval Letter (if applicable)
- 8) Confirmation of receipt of management plan from Investigational Drug Pharmacy (if applicable)
- 9) Research Funding Proposal (if applicable)
- 10) Medically Responsible Investigator CV or Biosketch (if applicable)
- 11) CV of Doctoral Student, Postdoctoral Scholar, Fellow, or Resident (if applicable)

VCU RESEARCH PLAN TEMPLATE

Use of this template is required to provide your VCU Research Plan to the IRB. Your responses should be written in terms for the non-scientist to understand. If a detailed research protocol (e.g., sponsor's protocol) exists, you may reference that protocol. **NOTE: If that protocol does not address all of the issues outlined in each Section Heading, you must address the remaining issues in this Plan. It is NOT acceptable to reference a research funding proposal.**

ALL Sections of the Human Subjects Instructions must be completed with the exception of the Section entitled "Special Consent Provisions." Complete that Section if applicable. When other Sections are not applicable, list the Section Heading and indicate "N/A."

NOTE: The Research Plan is required with ALL submissions and MUST follow the template, and include version number or date, and page numbers.

DO NOT DELETE SECTION HEADINGS OR THE INSTRUCTIONS.

I. TITLE

MANAGING THE HEALTHCARE NEEDS OF ADOLESCENTS WITH AUTISM SPECTRUM DISORDER: A PARENT'S EXPERIENCE

II. STAFFING

A. In the table below (add additional rows as needed), indicate: (1) key project personnel including the principal investigator and individuals from other institutions, (2) their qualifications, and (3) a brief description of their responsibilities.

NAME OF INDIVIDUAL	QUALIFICATIONS	RESPONSIBILITIES
Rita H. Pickler	PhD, RN, PNP-BC, FAAN	Principal Investigator
Julie A. Strunk	MSN, RN, doctoral candidate	Student investigator will serve as the primary contact for the study and be responsible for all data collection.

B. Describe the process that you will use to ensure that all persons assisting with the research are adequately informed about the protocol and their research-related duties and functions.

The PI will provide training to the student investigator as a function of the dissertation process. No other personnel are involved in this research.

III. CONFLICT OF INTEREST

Describe how the principal investigator and sub/co-investigators might benefit from the subject's participation in this project or completion of the project in general. Do not describe (1) academic recognition such as publications or (2) grant or contract based support of VCU salary commensurate with the professional effort required for the conduct of the project

The researchers will not financially benefit from subjects' participation or completion of this project.

IV. RESOURCES

Briefly describe the resources committed to this project including: (1) time available to conduct and complete the research, (2) facilities where you will conduct the research, (3) availability of medical or psychological resources that participants might require as a consequence of the research (if applicable), and (4) financial support.

The student investigator will be conducting this research full time as a fulfillment of her dissertation requirements. Interview sessions will be conducted in a private office at the James Madison University Institute for Innovation in Health and Human Services which is located in Harrisonburg, Virginia. Medical resources will not be required for the study participants. Psychological resources will be provided using a list of counseling services. The study is not funded.

V. HYPOTHESIS

Briefly state the problem, background, importance of the research, and goals of the proposed project.

Many scholars have found that parenting an adolescent with an autism spectrum disorder (ASD) can be very stressful because of the number and nature of symptoms associated with the disorder. Parents often experience significant challenges with their adolescent's inability to communicate effectively and their difficulty in learning (Phetrasuwan & Miles, 2009). In conjunction with these difficulties, parents are required to be vigilant about and manage inappropriate and sometimes aggressive or violent behaviors (Phetrasuwan & Miles, 2009). Extra care is needed due to the adolescent's lack of self-care skills and ongoing dependency needs (Phetrasuwan & Miles, 2009). Advocacy for the adolescent is often needed within the school setting, the medical setting, and the social setting (Phetrasuwan & Miles, 2009). Often times, parents may experience stigma from society (Gray, 1993), and worry about their adolescent's future for independent living (Koegel, Schreibman, Loos, Dirlich-Wilhelm, Dunlap, Robbins, et al., 1992; Little & Clark, 2006).

Family plays an important part in the environment of the adolescent and is central in their developmental outcomes (Sameroff, 1990; Altieri & von Kluge, 2009). According to Olson and colleagues (1985) and Seligman & Darling (1997), a well-functioning family has a good balance of cohesiveness and adaptability. Cohesion, as defined by Olsen (1985), is the emotional bonding between family members. Adaptability is defined as the family's ability to change in response to a stressful situation (Olsen, 1985). When there is an upset in the balance of cohesion and adaptability of a family, their functioning styles tend to change. Most families rely on social support, learn coping behaviors, and change the way an experience is interpreted in order to refurbish the balance in the family system (Patterson 1988; Altieri & von Kluge, 2009). Although families may typically establish their functional styles early, these functional styles change significantly upon discovery that their child has a disability (Altieri & von Kluge, 2009). Families who have a child with autism often experience a change in their functional styles due to the ambiguity of the diagnosis, the severity and duration of the disorder, and the child's lack of adherence to social norms (Bristol, 1984; Altieri & von Kluge, 2009).

In response to these identified challenges in the current literature, previous researchers have suggested (a) looking at parental stress; (b) looking at perceptions of caregivers; (c) examining family functioning and coping; and (d) investigating adverse effects on mothers (Phetrasuwan & Miles, 2009; Higgins, Bailey, & Pearce, 2005; Lee, Lopata, Volker, Thomeer, Nida, et al., 2009; Kelly, Garnett, Attwood, & Peterson, 2008; Altieri & von Kluge, 2009).

While the profession of nursing has had a long history in the care and advocacy of vulnerable populations, including parents of children with disabilities, no articles have been found in the current nursing literature that address the experience of parents who manage the healthcare needs of an adolescent with -autism spectrum disorder. Evidence-based nursing practice must conscientiously use the current best evidence in making decisions about the care of individual clients and the delivery of healthcare services to the most vulnerable, including parents of adolescents who have an autism spectrum disorder.

The overall goals of this project are to examine the perceptions of parents of adolescents with ASD on managing the healthcare needs of their children and to strive to understand the meaning of that experience.

VI. SPECIFIC AIMS

The specific aims of this study are to explore the experience of parents of adolescents with ASD in managing the healthcare needs of their children and to make meaning of their experience.

VII. BACKGROUND AND SIGNIFICANCE

Parenting an adolescent with ASD can be a challenging and unique experience. Autism is now considered the fastest growing developmental disability in the nation, affecting one in 150 children and is now considered to be the third most common childhood disorder, more common than Down Syndrome and childhood diabetes combined (CDC, 2010). It occurs more frequently than childhood cancer, cystic fibrosis, and multiple sclerosis together (Autism Society of American, 2009). An estimated 1.5 million individuals in the U.S. and tens of millions worldwide are affected by autism and government statistics suggest the prevalence rate of autism is increasing 10-17 percent annually (CDC, 2010). There is no established explanation for this increase, although improved diagnosis and environmental influences are two reasons often considered.

After performing an integrative review on the perceptions of parents of children with ASD, it was found that two major themes emerged: stress and the need for social support. No studies were found that reflected the parent's perception or experience of managing the healthcare needs of the adolescent with ASD. While the profession of nursing has had a long history in the care and advocacy of vulnerable populations, including parents of children with disabilities, no articles were found in the current nursing literature that address a parent's perception of meeting the health care needs of the adolescent who has autism. Evidence-based nursing practice dictates the use of applying best practices to any decisions involving the care of individual clients. This includes ensuring delivery of healthcare services to the most vulnerable populations, which would encompass parents of adolescents with ASD. With the increasing numbers of children being diagnosed with ASD and with autism becoming a prominent topic in the health and educational fields, the importance of exploring the lived experience of those parents managing the healthcare needs of the ASD adolescent cannot be over stated. It is only from hearing their individual stories that researchers can discover how to work with and provide services for these individuals.

An adolescent's autism diagnosis affects every member of the family in numerous ways (Beresford, 1994; Prilleltensky and Nelson, 2000; Strunk, 2010). Parents and/or caregivers often place their primary focus on helping their adolescent with ASD, which may put strains on their marriage, other children, work, finances, and personal relationships and responsibilities (Raina, O'Donnell, Schweltnus, Rosenbaum, King, Brehaut, Russell, Swinton, King, Wong, Walter, & Wood, 2004; Strunk, 2010). Parents have to shift much of their resources of time and money towards providing treatment and interventions for their adolescents, to the exclusion of other priorities (Raina et al., 2004).

Adolescents with ASD often suffer from co-morbidities such as tuberous sclerosis complex, fragile x syndrome, Down syndrome, and Prader-Willi syndrome to name a few (Zafeiriou, Ververi, Vargiami, 2007). These individuals usually display problems related to neurologic issues as well as nutritional, gastrointestinal and orthopedic problems (Souders, DePaul, Freeman, & Levy, 2002; Strunk, 2009). Due to the lack of specific pathophysiology, adolescents with ASD are often treated based on their symptomology and many are on a plethora of medications (Cole, 2008; Strunk, 2009).

It should be kept in mind that adolescents with autism have the same basic healthcare needs as those adolescents who are without disabilities (Cole, 2008; Strunk, 2009). Many are susceptible to risky health behaviors such as exploration and experimentation with smoking, alcohol, and drug use (Klein & Wilson, 2002). They also experience high levels of stress, decreased physical activity, unsafe sexual activity, depression, and suicide (Klein & Wilson, 2002). Therefore, the behavioral and medical needs of an adolescent with ASD can complicate familial relationships, creating a stressful environment in which to live and function in.

Many scholars have found that parenting an adolescent with an ASD can be very stressful because of the number and nature of symptoms associated with the disorder. Parents often experience significant challenges with their adolescent's inability to communicate effectively and their difficulty in learning (Phetrasuwan & Miles, 2009). In conjunction with these difficulties, parents are required to be vigilant about and manage inappropriate and sometimes aggressive or violent behaviors (Phetrasuwan & Miles, 2009). Extra care is needed due to the adolescent's lack of self-care skills and ongoing dependency needs (Phetrasuwan & Miles, 2009). Advocacy for the adolescent is often needed within the school setting, the medical setting, and the social setting (Phetrasuwan & Miles, 2009). Often times, parents may experience stigma from society (Gray, 1993), and worry about their adolescent's future for independent living (Koegel, Schreibman, Loos, Dirlich-Wilhelm,

Dunlap, Robbins, et al., 1992; Little & Clark, 2006).

In response to these identified challenges in the current literature, previous researchers have suggested (a) looking at parental stress; (b) looking at perceptions of caregivers; (c) examining family functioning and coping; and (d) investigating adverse effects on mothers (Phetrasuwan & Miles, 2009; Higgins, Bailey, & Pearce, 2005; Lee, Lopata, Volker, Thomeer, Nida, et al., 2009; Kelly, Garnett, Attwood, & Peterson, 2008; Altieri & von Kluge, 2009).

Autism Spectrum Disorder is a general term used to describe a group of complex developmental brain disorders known as Pervasive Developmental Disorders (PDD) (Lord, Risi, DiLavore, Shulman, Thurm, & Pickles, 2006). The other pervasive developmental disorders are PDD-NOS (Pervasive Developmental Disorder – Not

Otherwise Specified), Asperger's Syndrome, Rett Syndrome and Childhood Disintegrative Disorder. The main signs and symptoms of autism involve problems in the following areas:

- Communication - both verbal (spoken) and non-verbal (unspoken, such as pointing, eye contact, and smiling)
- Social - such as sharing emotions, understanding how others think and feel, and holding a conversation
- Routines or repetitive behaviors (also called stereotyped behaviors) - such as repeating words or actions, obsessively following routines or schedules, and playing in repetitive ways (Lord et al., 2006)

ASDs begin before the age of 3 and last throughout a person's life, although symptoms may improve over time (Lord et al., 2006). Some children with an ASD show hints of future problems within the first few months of life (Lord et al., 2006). In others, symptoms might not show up until 24 months or later (Lord et al., 2006). Some children with an ASD seem to develop normally until around 18 to 24 months of age and then they stop gaining new skills, or they lose the skills they once had (Lord et al., 2006). Diagnosing ASDs can be difficult since there is no medical test to diagnose the disorders. Doctors look at the child's behavior and development to make a diagnosis. ASDs can sometimes be detected at 18 months or younger. By age 2, a diagnosis by an experienced professional can be considered very reliable (Lord et al., 2006). However, many children do not receive a final diagnosis until much older. This delay means that children with an ASD might not get the help they need.

This study is important because it will allow for the understanding of why families with adolescents having ASD are more likely to have unmet needs for specific health care services, delayed or foregone care, difficulty receiving referrals, and care that is not family centered (Kogan, Strickland, Blumberg, Singh, Perrin, & van Dyck, 2008). With the increasing numbers of children being diagnosed with an ASD and with autism becoming a prominent topic in the health and educational fields, it is important to explore the experiences of those individuals experiencing the affects of managing the healthcare needs of adolescents with ASD. It is only from hearing their individual stories that researchers can discover how to work with and provide services for these individuals. Qualitative approaches, including open-ended interviews, would allow for interaction between the participants and the researcher and would allow the investigator to understand the meaning of the totality of the experience of parents managing the healthcare needs of the adolescent with ASD, a phenomenon still requiring further research.

Using description would allow the researcher to use language that articulates the parent's experience of managing the healthcare needs of an adolescent with ASD. Through description, the researcher includes explanations, constructions, and interpretations in order to articulate what has been experienced (Giorgi, 1997). Experiences become the basic data from which the nurse researcher works. According to Husserl (1970), the search for that experience, or essence, allows the researcher to present what has been found by others. The experience, or essence, is that which holds the parts or aspects of the phenomenon together (Giorgi, 1997). Through sharing the experience, the researcher continually looks for themes that have interconnectedness. Although the experiences of another cannot be known, the attitude should be that of wanting to understand the individual's world through their eyes and their experiences as far as possible. Together, the researcher and the individual can then probe those experiences fully and understand them (Daniels, 2005). When the researcher

uses the phenomenological method, he or she must continually examine and reexamine their biases and presuppositions (Daniels, 2005).

VIII. PRELIMINARY PROGRESS/DATA REPORT

If available.

Not applicable

IX. RESEARCH METHOD AND DESIGN

Include a brief description of the project design including the setting in which the research will be conducted and procedures. If applicable, include a description of procedures being performed already for diagnostic or treatment purposes.

Through the use of Moustakas' phenomenological approach, there will be a better understanding of the lived experience of parents who manage their ASD adolescent's healthcare needs and to allow the investigator to understand the meaning of their experience. This is important because there have been no other studies examining this issue. According to Moustakas, the nature of the lived experience allows the individual to focus on seeing, listening, touching, and thinking on what that experience is in its essences (Moustakas, 1994). The researcher can examine the experience for what it is, under what conditions it occurs, from what frame of reference, and what its possible meanings are (Moustakas, 1994). By turning to the lived experience, the researcher can describe in detail the whole account of an issue, problem, situation, or experience, using qualities and properties from specific contexts or perspectives, so that the experience takes on a vivid or essential meaning, a clear picture of what is (Moustakas, 1994).

Phenomenological studies do not require a specific number of participants. More importantly, phenomenological studies need to have enough participants to adequately explore the phenomenon being studied. Creswell (1998) recommended that the phenomenologist interview a small number of individuals, no more than 10. With this in mind, 10 parents (mother, father, or both) of adolescents (between the ages of 10 to 18) with Autism Spectrum Disorder will be interviewed for this study. Moustakas (1994) recommended participants be selected according to two criteria: (a) they are experiencing the phenomenon being studied, and (b) they are willing to participate in the study and willing to be interviewed. Parents will be purposefully chosen to participate in this study because of their experience in managing the healthcare needs of an adolescent who has ASD and their willingness to share their experience.

Participants will be recruited by direct solicitation through the use of printed flyers publicizing the proposed study (see flyer in Appendix A). These flyers will be posted at the James Madison University Department of Nursing, Harrisonburg, Virginia, Kluge Children's Rehabilitation Center, Charlottesville, Virginia, and Institute for Innovation in Health and Human Services, Harrisonburg, Virginia. A flyer will also be sent to the Shenandoah Valley Autism Partnership at svap@valleyautism.org and James Madison University T/TAC at sally.chappel@gmail.com. An advertisement will be posted in the Daily News Record, the Staunton News Leader, and the Valley Banner to run for two consecutive days. Prospective participants will contact the PI or student investigator. Following that contact, at which time the study will be explained to the prospective participant, the prospective participant will be sent a letter explaining the nature of the study along with a consent form. The letter will include a description of the study, the purpose, and procedures as well as confirmation of an appointment time that suits the participant's schedule. The consent form will be collected at the time of the interview. The interviews will take place in a quiet office at the James Madison University Institute for Innovation in Health and Human Services. Participants will be expected to provide their own childcare as interviews will take place without their children being present. Each interview will be audiotaped. The length of interviews will vary depending on the amount of information that each participant is willing to share; interviews will not exceed three hours. Inclusion criteria include: (a) must be the parent or a child between the ages of 10 and 18 who has a diagnosis of Autism Spectrum Disorder and who has guardianship the child; (b) the parent/s must be able to speak and read English; and (c) the child must have at least one on-going health care need in addition to ADS. Exclusion criteria include: (a) parents who are not the primary caregivers

of the child; (b) parents of children with ASD who were adopted.

The interview will be an interactive process between the participant and the researcher. The questions will be open ended and follow-up questions will be used to assist in clarifying and understanding the information presented. A general guide of questions will include asking participants what it is like managing the healthcare needs of an adolescent with ASD and how this affects them and those in their immediate family. Each participant will be informed that the information will be shared with the public by a written manuscript which will be submitted to a peer-reviewed journal. Participants will be assured that all identifying information will be removed. The student researcher will be responsible for transcribing all data from the audiotapes. Transcripts will be stored at the VCU School of Nursing. The student researcher will use one working copy of the transcripts for analysis.

X. PLAN FOR CONTROL OF INVESTIGATIONAL DRUGS, BIOLOGICS, AND DEVICES.

For investigational drugs and biologics: IF IDS is not being used, attach the IDS confirmation of receipt of the management plan. See item #11 on Initial Review form.

For investigational and humanitarian use devices (HUDs): Describe your plans for the control of investigational devices and HUDs including: (1) how you will maintain records of the product's delivery to the trial site, the inventory at the site, the use by each subject, and the return to the sponsor or alternative disposition of unused product(s); (2) plan for storing the investigational product(s)/ HUD as specified by the sponsor (if any) and in accordance with applicable regulatory requirements; (3) plan for ensuring that the investigational product(s)/HUDs are used only in accordance with the approved protocol; and (4) how you will ensure that each subject understands the correct use of the investigational product(s)/HUDs (if applicable) and check that each subject is following the instructions properly (on an ongoing basis).

NOT APPLICABLE

XI. DATA ANALYSIS PLAN

For investigator-initiated studies.

Data will be analyzed using Moustakas' (1994) method of analysis of phenomenological data. This method will include the following: horizontalization of participants' statements (separating statements that pertain to the phenomenon and those that do not), reduction and elimination of data (looking for statements that contain a moment of experience necessary for understanding the lived experience and the ability of the statement to be labeled), clustering and thematizing invariant constituents (grouping statements into core themes), validation of invariant constituents (checking themes against the transcript of the participant to ensure that the statements match and that the statements express what the participant conveys), individual textural descriptions (explanation of the core themes as they apply to a particular participant's lived experience – participants will be given a copy of their textural description to read to ensure accuracy), and individual structural descriptions (looking at underlying feelings and thoughts experienced by the participants). The final two steps will include creating a textural-structural description of the meanings and essence of the experiences for each participant and developing a composite description of the meanings and essences of the experience for the group as a whole.

This study will strive to establish trustworthiness by including credibility, transferability, dependability, and confirmability. Credibility is enhanced by the following techniques: (a) prolonged engagement, (b) triangulation, (c) peer debriefing, (d) negative case analysis, (e) referential adequacy, and (f) member checking. This study will maximize credibility by using three of these strategies: prolonged engagement, peer debriefing, and member checking.

Prolonged engagement requires that the researcher use extended time to reflect on journals and field notes and test how their perceptions of the experience have changed over that extended time frame. According to Guba (1981), researchers need to be able to show that sufficient time was spent in the field in order to justify their characterizations of the experience. In this case, the student researcher will spend at least three hours with each participant in the interview session.

Peer debriefing requires that the researcher select one or more peers who will serve as a guide and discuss interpretations and concerns with those colleagues. According to Guba (1981), it is important for

researchers to regularly detach themselves from the field, and to seek counsel from other professionals who are willing to perform the debriefing function. In this case, the student researcher has a doctoral colleague who knowledgeable of the approach and is willing to read and discuss any interpretations or concerns that are found.

Member checking requires that the researcher obtain feedback from the research participants (Lincoln & Guba, 1985). This feedback is particularly useful when the analysis and interpretation have been made and conclusions have been drawn (Tutty, Rothery, & Grinnell, 1996; Guba, 1981). In this case, the student researcher will invite the participants to read their composite structural/textural stories in order to allow for any changes that need to be made and to affirm that what has been written is an accurate portrayal of their experiences. If requested by the participant, a second interview will occur.

The responsibility for transferability falls not only on the original researcher but on the person seeking to apply the information (Lincoln and Guba, 1985). The prospective study may have transferability to other parents who manage the healthcare needs of their adolescent with ASD; ultimately, it is up to the individual seeking the application to determine if the data is applicable. The researcher can facilitate transferability by providing thick descriptions from the participants' words and providing rich narratives of their experiences. Dependability will be achieved by maintaining an inquiry audit (Lincoln and Guba, 1985). This audit will consist of examining the data-collection process and the data process by keeping a reflexive journal, maintaining a notebook with transcripts and the researcher's reactions and thoughts, and consulting an experienced and qualified outside expert to review or audit the consistency of the research process.

To enhance confirmability an audit-trail record will be created during each phase of the data collection and data analysis process (Lincoln and Guba, 1985). It will consist of the following: (1) raw data, interview, audiotapes, transcripts; (2) data-analysis materials such as write-ups, interview notes, results, findings, interpretations, themes, definitions; (3) all process notes describing methodology and trustworthiness; and (4) all materials concerning expectations, predictions and intentions, question development and data collection. At the completion of this study, the principle investigator will examine the audit trail and verify whether procedures were followed and interpretations were reasonable (Guba, 1981).

The final technique is reflexive journaling. The researcher will maintain a daily journal that includes biases, thoughts, reflections, daily schedules, and a methodological log. It is important to recognize that a reflective level of self-awareness and self-consciousness is required to begin to capture the perspectives through which the world is viewed and that it may be impossible to take hold of the unconscious filters through which we experience events (Bell & Newby, 1977; Bell & Roberts, 1984; Mauthner & Doucet, 2003).

XII. DATA AND SAFETY MONITORING

- **If the research involves greater than minimal risk and there is no provision made for data and safety monitoring by any sponsor, include a data and safety-monitoring plan that is suitable for the level of risk to be faced by subjects and the nature of the research involved.**
- **If the research involves greater than minimal risk, and there is a provision made for data and safety monitoring by any sponsor, describe the sponsor's plan.**
- **If you are serving as a Sponsor-Investigator, identify the Contract Research Organization (CRO) that you will be using and describe the provisions made for data and safety monitoring by the CRO. Guidance on additional requirements for Sponsor-Investigators is available at <http://www.research.vcu.edu/irb/wpp/flash/X-2.htm>**

The proposed project not a clinical trial. However, the student investigator is available 24 hours a day by cell phone or home phone; these numbers are provided to participants. The student investigator will meet monthly with the PI (dissertation chair) to monitor for safety issues, particularly parent distress. In addition, the study process will be reviewed for unexpected occurrences or alterations. Any changes will be examined for their relationship to the project protocol. Reports of these chair meetings will be reviewed at the full progress meetings of the Dissertation Committee.

Because the planned project involves minimal risk, no adverse events are expected to occur as a direct result of participant participation. However, should any event occur that might be related to study participation, the study investigator will assume responsibility for notification of the designated care providers and any referral for recommended treatment, as well as notification of the VCU IRB. Adverse event reporting forms and

procedures are available on-line at: <http://www/orsp.vcu.edu/irb>.

XIII. MULTI-CENTER STUDIES

If VCU is the lead site in a multi-center project or the VCU PI is the lead investigator in a multi-center project, describe the plan for management of information that may be relevant to the protection of subjects, such as reporting of unexpected problems, project modifications, and interim results.

Not applicable

XIV. INVOLVEMENT OF NON-VCU INSTITUTIONS/SITES (DOMESTIC AND FOREIGN)

1. Provide the following information for each non-VCU institution/site (domestic and foreign) that has agreed to participate:

- Name of institution/site
- Contact information for institution/site

Not applicable

2. For each institution, indicate whether or not it is “engaged” in the research (see OHRP’s guidance on “Engagement of Institutions in Research” at <http://www.hhs.gov/ohrp/humansubjects/guidance/engage08.html>.)

Not applicable

3. Provide a description of each institution’s role (whether engaged or not) in the human subjects research, adequacy of the facility (in order to ensure human subject safety in the case of an unanticipated emergency), responsibilities of its agents/employees, and oversight that you will be providing in order to ensure adequate and ongoing protection of the human subjects. You should only identify institutions that have agreed to participate. If additional institutions agree to participate at a later time, they must be added by amendment to the protocol.

Not applicable

4. For each institution that is “engaged” provide an OHRP Federal wide Assurance (FWA) # if: (1) the research is not exempt, AND (2) the research involves a DIRECT FEDERAL award made to VCU (or application for such).

NOTE: Additional guidance at <http://www.research.vcu.edu/irb/wpp/flash/XVII-6.htm>, and <http://www.research.vcu.edu/irb/wpp/flash/XVII-11.htm>.

Not applicable

XV. INVOLVEMENT OF INDEPENDENT INVESTIGATORS

INDEPENDENT INVESTIGATOR: an individual who is acting independently and not acting as an agent or employee of any institution or facility while carrying out his or her duties in the research protocol. Additional guidance at <http://www.research.vcu.edu/irb/wpp/flash/XVII-15.htm>.

ENGAGEMENT IN RESEARCH: An independent investigator becomes "engaged" in human subjects research when he/she (i) intervenes or interacts with living individuals for research purposes; or (ii) obtains individually identifiable private information for research purposes [45 CFR 46.102(d)-(f)]. See OHRP’s guidance on “Engagement of Institutions in Research” at <http://www.hhs.gov/ohrp/humansubjects/guidance/engage08.html>.

1. Provide a list of independent investigators.

2. For each independent investigator indicate whether or not he/she is “engaged” or “not engaged” in the research

3. For each independent investigator who is “engaged”: (1) describe his/her role with human subjects/identifiable

human data, AND (2) describe YOUR oversight of his/her involvement.

NOT APPLICABLE

NOTE: If an independent investigator is “engaged,” and the research is (1) not exempt AND (2) involves a DIRECT FEDERAL award made to VCU (or application for such), the independent investigator must sign a formal written agreement with VCU certifying terms for the protection of human subjects. For an agreement to be approved: (1) the PI must directly supervise all of the research activities, (2) agreement must follow the ORSP template, (3) IRB must agree to the involvement of the independent investigator, AND (4) agreement must be in effect prior to final IRB approval.

XVI. HUMAN SUBJECTS INSTRUCTIONS (Be sure to use the sub-headings under A-I)

ALL sections of the Human Subjects Instructions must be completed with the exception of the section entitled “Special Consent Provisions.” Complete that section if applicable.

A. DESCRIPTION

Provide a detailed description of the proposed involvement of human subjects or their private identifiable data in the work.

This study will involve 10 parents (mother, father, or both) who manage the healthcare needs of an adolescent, age 10-18 years, with Autism Spectrum Disorder. If both the mother and father are willing to participate, they will be counted as 1 participant and not as 2 individual participants. Participants must meet inclusion and exclusion criteria and must be able to read and speak English. A flyer, advertising the study will be placed at the following locations for recruitment purposes: the JMU Department of Nursing, Harrisonburg, Virginia, Kluge Children’s Rehabilitation Center, Charlottesville, Virginia, and the Institute for Innovation in Health and Human Services, Harrisonburg, Virginia. A flyer will also be sent to the Shenandoah Valley Autism Partnership at svap@valleyautism.org and James Madison University T/TAC at sally.chappel@gmail.com. An advertisement will be posted in the Daily News Record, the Staunton News Leader, and the Valley Banner to run for two consecutive days. Eligible participants will be given a full explanation of the study and asked to sign a consent form. No private identifiable data will be collected. Participants will be interviewed once for no longer than three hours. Participants will be asked to review a description of their experience that will be written by the student investigator.

B. SUBJECT POPULATION

Describe the subject population in terms of sex, race, ethnicity, age, etc., and your access to the population that will allow recruitment of the necessary number of participants. Identify the criteria for inclusion or exclusion of any subpopulation and include a justification for any exclusion. Explain the rationale for the involvement of special cases of subjects, such as children, pregnant women, human fetuses, neonates, prisoners or others who are likely to be vulnerable. If you plan to allow for the enrollment of Wards of the State (or any other agency, institution, or entity), you must specifically request their inclusion and follow guidance on Wards and Emancipated Minors in the VCU IRB Written Policies and Procedures (specifically WPP#: XV-3) available at <http://www.research.vcu.edu/irb/wpp/flash/XV-3.htm>.

The sample will consist of 10 parents who manage the healthcare needs of an adolescent with autism spectrum disorder.

Inclusion criteria include: (a) must be the parent or a child between the ages of 10 and 18 who has a diagnosis of Autism Spectrum Disorder and who has guardianship the child; (b) the parent/s must be able to speak and read English; and (c) the child must have at least one on-going health care need in addition to ADS.

Exclusion criteria include: (a) parents who are not the primary caregivers of the child; (b) parents of children with ASD who were adopted.

C. RESEARCH MATERIAL

Identify the sources of research material obtained from individually identifiable living human subjects in the form of specimens, records, or data. Indicate whether the material or data will be obtained specifically for research purposes or whether use will be made of existing specimens, records, or data.

The interview will be an interactive process between the participant and the student investigator with the student investigator collecting all data. The questions will be open ended and follow-up questions will be used to assist in clarifying and understanding the information presented. A general guide of questions may include asking participants what it is like managing the healthcare needs of an adolescent with an ASD and how this affects them and those in their immediate family. All data will be obtained specifically for research purposes.

D. RECRUITMENT PLAN

Describe in detail your plans for the recruitment of subjects including: (1) how potential subjects will be identified (e.g., school personnel, health care professionals, etc), (2) how you will get the names and contact information for potential subjects, and (3) who will make initial contact with these individuals (if relevant) and how that contact will be done. If you plan to involve special cases of subjects, such as children, pregnant women, human fetuses, neonates, prisoners or others who are likely to be vulnerable, describe any special recruitment procedures for these populations.

Participants will be recruited using study advertisements (flyers) distributed in print (see Appendix A) at the following: the JMU Department of Nursing, Harrisonburg, Virginia, Kluge Children's Rehabilitation Center, Charlottesville, Virginia, and Institute for Innovation in Health and Human Services, Harrisonburg, Virginia. A flyer will also be sent to the Shenandoah Valley Autism Partnership at svap@valleyautism.org and James Madison University T/TAC at sally.chappel@gmail.com. Participants may self-identify as potential participants by responding to advertisements and calling the study investigator at her telephone number or contacting her through an email address (each identified in advertising materials). The student investigator will explain the study to the potential participant who will be screened based upon inclusion and exclusion criteria. If parents meet the study criteria and desire to participate, an appointment will be made for them to meet with the study investigator at a convenient time. A letter confirming the appointment date and time and a copy of the consent form will be sent to the participant. At the initial meeting, the student investigator will review the study and obtain informed consent. The data collection visit will be conducted in a private room at the Institute for Innovation in Health and Human Services. Following consent and enrollment, the data collection visit, which consists of open ended questions through an interview process, should take no longer than 3 hours. Participants will be asked to read and comment on a written description of their experience.

E. POTENTIAL RISKS

Describe potential risks whether physical, psychological, social, legal, or other and assess their likelihood and seriousness. Where appropriate, describe alternative treatments and procedures that might be advantageous to the subjects.

As the questions may involve sensitive topics, there may be potential for psychological risk to the subjects. Therefore, the student investigator will discontinue the interview at the request of the participants and will make available a list of psychological resources that can be accessed by the participants.

F. RISK REDUCTION

Describe the procedures for protecting against or minimizing potential risk. Where appropriate, discuss provisions for ensuring necessary medical or professional intervention in the event of adverse events to the subjects. Also, where appropriate, describe the provisions for monitoring the data collected to ensure the safety of subjects.

As part of the process involved in obtaining written informed consent, participants will be given a copy of the informed consent form. The PI and the student investigator are both licensed, registered nurses. Because the nature of the interview questions is not sensitive, this poses almost no risk to participants. Contact information for the PI and the student investigator is provided on the consent form.

G. ADDITIONAL SAFEGUARDS IF ANY PARTICIPANTS WILL BE VULNERABLE

Describe any additional safeguards to protect the rights and welfare of participants if you plan to involve special cases of subjects, such as children, pregnant women, human fetuses, neonates, prisoners or others who are likely to be vulnerable. Safeguards to protect the rights and welfare of participants might relate to Inclusion/Exclusion Criteria: (“Adults with moderate to severe cognitive impairment will be excluded.” “Children must have diabetes. No normal controls who are children will be used.”) Consent: (“Participants must have an adult care giver who agrees to the participant taking part in the research and will make sure the participant complies with research procedures.” “Adults must be able to assent. Any dissent by the participant will end the research procedures.”) Benefit: (“Individuals who have not shown benefit to this type of drug in the past will be excluded.”).

Not applicable

H. CONFIDENTIALITY

Describe how the confidentiality of data collected as part of this project will be protected including pre-screening data (e.g., physical controls on the data; access controls to the data; coding of data; legal controls, such as a Federal Certificate of Confidentiality; statistical methods; or reporting methods).

Confidentiality of participant data is the primary safety-related issue in this study. Participants’ identities will be protected. Each data record will be assigned an arbitrary code number by the student investigator and then identifying information will be removed from the data record and attached to the consent form, which will be kept in a locked file accessible only by the study personnel.

I. PRIVACY

Describe how the privacy interests of subjects will be protected where privacy refers to persons and their interests in controlling access to themselves, and assess their likely effectiveness. Identify what steps you will take for subjects to be comfortable: (1) in the research setting and (2) with the information being sought and the way it is sought.

Study participants and information will only be accessible to the student investigator and the PI who will maintain participant privacy. Each study visit will be conducted in a private room to ensure participants’ privacy.

J. RISK/BENEFIT

Discuss why the risks to subjects are reasonable in relation to the anticipated benefits to subjects and in relation to the importance of the knowledge that may reasonably be expected to result. If a test article (investigational new drug, device, or biologic) is involved, name the test article and supply the FDA approval letter.

There are no studies that have been conducted on the parent’s perceptions on managing the healthcare needs of the adolescent with ASD. With the increasing numbers of children being diagnosed with ASD and with autism becoming a prominent topic in the health and educational fields, it is important to explore the lived experience of those individuals experiencing the affects of ASD. It is only from hearing their individual stories that researchers can discover how to work with and provide services for these individuals.

K. COMPENSATION PLAN

Compensation for subjects (if applicable) should be described, including possible total compensation, any proposed bonus, and any proposed reductions or penalties for not completing the project.

Not applicable

L. CONSENT ISSUES**1. CONSENT PROCESS**

Indicate who will be asked to provide consent/assent, who will obtain consent/assent, what language (e.g., English, Spanish) will be used by those obtaining consent/assent, where and when will consent/assent be obtained, what steps will be taken to minimize the possibility of coercion or undue influence, and how much time will subjects be afforded

to make a decision to participate.

Informed consent (see Appendix C) will be obtained in a private setting. Potential participants can take as much time as needed to read or discuss the consent with the student investigator, family or friends before making their decision. Furthermore, explanation of the study will be provided verbally and in writing. Participants will be allowed to ask questions or call the study investigator to discuss any concerns at any time.

2. SPECIAL CONSENT PROVISIONS

If some or all subjects will be cognitively impaired, or have language/hearing difficulties, describe how capacity for consent will be determined. Please consider using the VCU Informed Consent Evaluation Instrument available at <http://www.research.vcu.edu/irb/guidance.htm>. If you anticipate the need to obtain informed consent from legally authorized representatives (LARs), please describe how you will identify an appropriate representative and ensure that their consent is obtained. Guidance on LAR is available at <http://www.research.vcu.edu/irb/wpp/flash/XI-3.htm>.

Not applicable

3. If request is being made to WAIVE SOME OR ALL ELEMENTS OF INFORMED CONSENT FROM SUBJECTS OR PERMISSION FROM PARENTS, explain why: (1) the research involves no more than minimal risk to the subjects, (2) the waiver or alteration will not adversely affect the rights and welfare of the subjects, (3) the research could not practicably be carried out without the waiver or alteration; AND (4) whether or not subjects will be debriefed after their participation. Guidance is available at <http://www.research.vcu.edu/irb/wpp/flash/XI-1.htm>. **NOTE:** Waiver is not allowed for FDA-regulated research unless it meets FDA requirements for Waiver of Consent for Emergency Research (see below).

Not applicable

4. If request is being made to WAIVE DOCUMENTATION OF CONSENT, provide a justification for waiver based on one of the following two elements AND include a description of the information that will be provided to participants: (1) the only record linking the subject and the research would be the consent document and the principal risk would be potential harm resulting from a breach of confidentiality. Subject will be asked whether they want documentation linking them with the research, and each subject's wishes will govern; or (2) the research presents no more than minimal risk of harm to subjects and involves no procedures for which written consent is normally required outside of the research context. Guidance is available at http://www.research.vcu.edu/irb/wpp/flash/wpp_guide.htm#XI-2.htm

Not applicable

5. If applicable, explain the ASSENT PROCESS for children or decisionally impaired subjects. Describe the procedures, if any, for re-consenting children upon attainment of adulthood. Describe procedures, if any, for consenting subjects who are no longer decisionally impaired. Guidance is available at <http://www.research.vcu.edu/irb/wpp/flash/XV-2.htm> and <http://www.research.vcu.edu/irb/wpp/flash/XVII-7.htm>.

Not applicable

6. If request is being made to WAIVE THE REQUIREMENT TO OBTAIN ASSENT from children age 7 or higher, or decisionally impaired subjects, explain why: (1) why some or all of the individuals age 7 or higher will not be capable of providing assent based on their developmental status or impact of illness; (2) the research holds out a prospect of direct benefit not available outside of the research; AND/OR (3) [a] the research involves no more than minimal risk to the subjects, [b] the waiver or alteration will not adversely affect the rights and welfare of the subjects, [c] the research could not practicably be carried out without the waiver or alteration; AND [d] whether or not subjects will be debriefed after their participation. Guidance is available at <http://www.research.vcu.edu/irb/wpp/flash/XV-2.htm>

Not applicable

7. If request is being made to waive consent for emergency research, see guidance at

Not applicable

8. If applicable, address the following issues related to GENETIC TESTING:

a. FUTURE CONTACT CONCERNING FURTHER GENETIC TESTING RESEARCH

Describe the circumstances under which the subject might be contacted in the future concerning further participation in this or related genetic testing research.

Not applicable

b. FUTURE CONTACT CONCERNING GENETIC TESTING RESULTS

If planned or possible future genetic testing results are unlikely to have clinical implications, then a statement that the results will not be made available to subjects may be appropriate. If results might be of clinical significance, then describe the circumstances and procedures by which subjects would receive results. Describe how subjects might access genetic counseling for assistance in understanding the implications of genetic testing results, and whether this might involve costs to subjects. Investigators should be aware that federal regulations, in general, require that testing results used in clinical management must have been obtained in a CLIA-certified laboratory.

Not applicable

c. WITHDRAWAL OF GENETIC TESTING CONSENT

Describe whether and how subjects might, in the future, request to have test results and/or samples withdrawn in order to prevent further analysis, reporting, and/or testing.

Not applicable

d. GENETIC TESTING INVOLVING CHILDREN OR DECISIONALLY IMPAIRED SUBJECTS

Describe procedures, if any, for consenting children upon the attainment of adulthood. Describe procedures, if any, for consenting subjects who are no longer decisionally impaired.

Not applicable

e. CONFIDENTIALITY

Describe the extent to which genetic testing results will remain confidential and special precautions, if any, to protect confidentiality.

Not applicable

APPENDICES

Appendix A Advertisement Flyer

Appendix B Newspaper Advertisement

Appendix C Confirmation Letter to Participants

Appendix D Thank you Letter to Participants

References:

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Appendix A:

Participants Needed for Research Study

Seeking parents of children with Autism Spectrum Disorder to participate in a research study at Virginia Commonwealth University School of Nursing

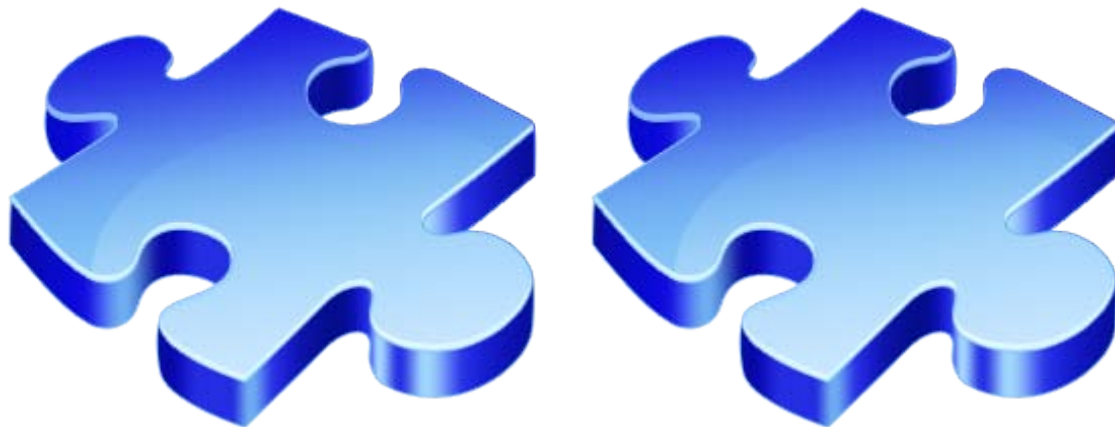
The purpose of this study is to examine the experiences of parents who have an adolescent child with Autism Spectrum Disorder.

Participation involves an interview, at the Faison School of Autism, consisting of several open-ended questions. Interview will last no longer than 3 hours. Childcare will not be provided.

Please call the following for more information about enrolling in the study:

540-564-1728 strunkja@vcu.edu

804-828-0721 rpickler@vcu.edu



Participants Needed for Research Study

Seeking parents of children ages 10 to 18 with Autism Spectrum Disorder to participate in a research study being conducted as part of a study at Virginia Commonwealth University School of Nursing by Julie Stunk, MS, RN.

The purpose of this study is to examine the experiences of parents who have an adolescent child with Autism Spectrum Disorder.

Participation involves an interview consisting of several open-ended questions. The interview will last no longer than 3 hours and will take place at the James Madison University Institute for Innovation in Health and Human Services. Childcare will not be provided.

If you are interested in participating in the study, please call or email Julie Stunk at 540-564-1728 (strunkja@vcu.edu) or you may contact her advisor, Dr. Rita Pickler at 804-828-0721 (rpickler@vcu.edu).

Confirmation Letter to Participants

Parent address here

Dear _____

Thank you for your interest in my dissertation research on the experience of managing the healthcare needs of the adolescent with Autism Spectrum Disorder. I value the unique contribution that you can make to my study and I am excited about the possibility of your participation in it. The purpose of this letter is to review what we have already discussed and to provide you a copy of the consent form, which we will sign when we meet.

The research I am doing is a qualitative study in which I am seeking comprehensive descriptions of your experience. In this way I hope to answer my question: “What is the experience of managing the healthcare needs of an adolescent with Autism Spectrum Disorder?”

Through your participation, I hope to understand what it is like to manage the healthcare needs of the adolescent with autism spectrum disorder. You will be asked to recall specific episodes, situations, or events that you experienced in seeking health care for your adolescent. I am seeking vivid, accurate, and comprehensive portrayals of what these experiences were like for you: your thoughts, feelings, and behaviors, as well as situations, events, places, and people connected with your experience.

I value your participation and thank you for the commitment of time, energy, and effort. We are scheduled to meet at the James Madison University Institute for Innovation in Health and Human Services on DATE at TIME. Child care will not be provided. If you have any further questions or if there is a problem with the date and time of our meeting, I can be reached at 540-564-1728. My dissertation advisor, Dr. Rita Pickler, can be reached if needed at 804-828-0721 (rpickler@vcu.edu).

With warm regards,

Julie A. Strunk, RN, MSN

Follow-up letter for participants

Date

Address

Dear _____

Thank you for meeting with me and sharing your parenting experience about managing the health care needs of your adolescent. I appreciate your willingness to share your unique and personal thoughts, feelings, events, and situations.

I have enclosed a summary of my analysis of my interview with you. I would appreciate your review of this analysis. Please ask yourself if this analysis represents your experience of managing the healthcare needs of your adolescent with Autism Spectrum Disorder. After reviewing the analysis, please feel free to add comments, with the enclosed red pen, that would further elaborate your experience(s), or if you prefer we can arrange to meet again and tape record your additions or corrections.

When you have reviewed the analysis and have had an opportunity to make changes and additions, please return it to me in the stamped, addressed envelope.

I greatly value your participation in this research study and your willingness to share your experience. If you have any questions or concerns, do not hesitate to call me at 540-564-1728. You may also call my dissertation advisor, Dr. Nancy McCain, at 804-828-3444, if needed.

With warm regards,

Julie A. Strunk, RN, MSN

P.S. You can keep the ink pen.

Conflict of Interest Disclosure Statement

No.:	_____
Rec'd by:	_____
Date:	_____
Actions:	_____
To COIRC:	_____
To File:	_____

Under VCU Research Policy, the Principal Investigator and all others who have responsibility for the design, conduct, or reporting of research, must disclose financial interests in any external entity that is related to the work to be conducted under the proposed project or is interested in the results of the project. Providing this information is mandatory. Any individual who voluntarily discloses financial interests related to extramurally supported research projects should also use this form. Under the Virginia Public Records Act, this information may be made available to the public upon request.

Principal Investigator: Rita Pickler, RN, PhD School/Dept: VCU School of Nursing
 Funding Entity: _____ Contract/Grant No: _____
 Title of Research Project: Managing the Healthcare Needs of Adolescents with ASD: A Parent's Experience

Reason for Disclosure: New Proposal Additional Support New Protocol New Investigator New Interest Obtained
 Revisions to Grant/Contract Grant/Contract Continuation

Disclosure and Certification

By signature below, each individual certifies that either no Financial Interest exists or that a complete listing of all financial interest is provided on a [Disclosure Supplement form](#). All individuals named below further acknowledge their responsibility to disclose any new Financial Interest obtained during the term of the award.

The Principal Investigator's signature certifies that all individuals required to make disclosures have been listed below.

A. Do you, your spouse, or dependent children have a Financial Interest in an external entity related to the work to be conducted under the project or interested in the results of the project? (See reverse for definitions of Financial Interests.) – Check response below adjacent to your signature.

B. If the project is funded, to the best of your knowledge, does any VCU employee have a financial interest, including an ownership or equity interest, in the sponsor? Check response below adjacent to your signature.

C. Project is Unfunded:

1. _____ Signature (PI) Date Rita Pickler Print or Type Name of Principal Investigator	A. <input checked="" type="checkbox"/> NO <input type="checkbox"/> YES, Supplement Form attached B. <input checked="" type="checkbox"/> NO <input type="checkbox"/> YES, Name
2. _____ Signature Date Julie A. Strunk Print or Type Name of Investigator	A. <input checked="" type="checkbox"/> NO <input type="checkbox"/> YES, Supplement Form attached B. <input checked="" type="checkbox"/> NO <input type="checkbox"/> YES, Name
3. _____ Signature Date Print or Type Name of Investigator	A. <input type="checkbox"/> NO <input type="checkbox"/> YES, Supplement Form attached B. <input type="checkbox"/> NO <input type="checkbox"/> YES, Name
4. _____ Signature Date Print or Type Name of Investigator	A. <input type="checkbox"/> NO <input type="checkbox"/> YES, Supplement Form attached B. <input type="checkbox"/> NO <input type="checkbox"/> YES, Name
5. _____ Signature Date Print or Type Name of Investigator	A. <input type="checkbox"/> NO <input type="checkbox"/> YES, Supplement Form attached B. <input type="checkbox"/> NO <input type="checkbox"/> YES, Name

(please attach additional pages as required)

Financial Interest(s): Financial Interests include but are not limited to:

- Income including salary, consulting payments, honoraria, reimbursement of expenses, royalty payments, dividends, loans from an entity, or any other payments or consideration with value, including payments made to a health sciences compensation plan, during the prior twelve months or anticipated in the next twelve months;
- Equity in the form of stock, stock options, warrants, business or commercial real estate, business or commercial loans to or from an entity, or any other investment or ownership interest;
- A management position, whether paid or unpaid, such as board member, director, officer, partner, advisor, or trustee;
- Ownership or other interest in an entity that is proposed as a subcontractor, consortium member, lessor or otherwise involved in the project;
- Intellectual property interest on a patent, patent application, or copyright assigned or licensed to a party other than The VCU Foundation.

Reporting is for the individual, his/her spouse and dependent children.

Specifically excluded from the definitions of financial interest are:

- Payments made by VCU and VCUHS, including salary, stipends, honoraria, royalty payments, reimbursement of expenses, or any other remuneration from the University;
- Income from seminars, lectures, or teaching engagements sponsored by public or nonprofit entities;
- Income from service on advisory committees or review panels or from editorial activities for public or nonprofit entities;
- Interest in mutual funds where the individual has no control over the selection of holdings

Appendix C:

RESEARCH SUBJECT INFORMATION AND CONSENT FORM

TITLE: Managing the Healthcare Needs of Adolescents with Autism Spectrum Disorder: A Parent's Experience

VCU IRB NO.:

SPONSOR:

This consent form may contain words that you do not understand. Please ask the study staff to explain any words that you do not clearly understand. You may take home an unsigned copy of this consent form to think about or discuss with family or friends before making your decision.

PURPOSE OF THE STUDY

The purpose of this research study is to find out about parents' experiences in managing the healthcare needs of adolescents with Autism Spectrum Disorder.

You are being asked to participate in this study because you have an adolescent with Autism Spectrum Disorder that requires management of healthcare needs.

DESCRIPTION OF THE STUDY AND YOUR INVOLVEMENT

If you decide to be in this research study, you will be asked to sign this consent form after you have had all your questions answered and understand what will happen to you.

In this study you will be asked to attend one interview session. The session will last for no longer than three hours. In the session, you will be asked to talk about what it is like to manage the healthcare needs of your adolescent with ASD. The meetings will be tape recorded so we are sure to get everyone's ideas, but no names will be recorded on the tape. You will be allowed to review and read any textual stories that you relate during the interview for accuracy and clarification. If desired, the participant can request a second interview. At the end of the study the student investigator will write an article for publication in a health care journal; she will ask you if you wish to read the article before the final version is prepared. You may decline to read the article.

Significant new findings developed during the course of the research which may relate to your willingness to continue participation will be provided to you.

RISKS AND DISCOMFORTS

Sometimes talking about these subjects causes people to become upset. Several questions will ask about things that have happened in your family that may have been unpleasant. You do not have to talk about any subjects you do not want to talk about, and you may leave the session at any time. If you become upset, the study staff will give you names of counselors to contact so you can get help in dealing with these issues.

BENEFITS TO YOU AND OTHERS

You may not get any direct benefit from this study, but, the information we learn from people in this study may help us design better programs for parents of adolescents with autism.

COSTS

There are no costs for participating in this study other than the time you will spend in the interview session.

ALTERNATIVES

The alternative is to not participate in this study.

CONFIDENTIALITY

Potentially identifiable information about you will consist of interview notes and recordings. Data is being collected only for research purposes. Your data will be identified by ID numbers, not names, and stored in a locked research area. There will be no personal identifying information kept about you. The data files will be password protected and deleted within 7 years of completion of the study. Access to all data will be limited to study personnel.

We will not tell anyone the answers you give us; however, information from the study and the consent form signed by you may be looked at or copied for research or legal purposes by Virginia Commonwealth University.

What we find from this study may be presented at meetings or published in papers, but your name will never be used in these presentations or papers.

The interview session will be audio taped, but no names will be recorded. At the beginning of the session, all participants will be asked to use initials only so that no names are recorded. The tapes and the notes will be stored in a locked cabinet. At the completion of the study, the tapes will be destroyed.

VOLUNTARY PARTICIPATION AND WITHDRAWAL

You do not have to participate in this study. If you choose to participate, you may stop at any time without any penalty. You may also choose not to answer particular questions that are asked in the study.

Your participation in this study may be stopped at any time by the study staff without your consent. The reasons might include:

- the study staff thinks it necessary for your health or safety;
- you have not followed study instructions;
- the sponsor has stopped the study; or
- administrative reasons require your withdrawal.

QUESTIONS

In the future, you may have questions about your participation in this study. If you have any questions, complaints, or concerns about the research, contact:

Rita H. Pickler, PhD, RN, PNP-BC, FAAN
Endowed Alumni Professor
Family and Community Health Nursing
VCU School of Nursing
1100 East Leigh St.
PO Box 980567
Richmond, VA 23298
Ph: (804) 828-0721
rpickler@vcu.edu

If you have any questions about your rights as a participant in this study, you may contact:

Office for Research
Virginia Commonwealth University
800 East Leigh Street, Suite 113
P.O. Box 980568
Richmond, VA 23298
Telephone: 804-827-2157

You may also contact this number for general questions, concerns or complaints about the research. Please call this number if you cannot reach the research team or wish to talk to someone else. Additional information about participation in research studies can be found at <http://www.research.vcu.edu/irb/volunteers.htm>.

CONSENT

I have been given the chance to read this consent form. I understand the information about this study. Questions that I wanted to ask about the study have been answered. My signature says that I am willing to participate in this study. I will receive a copy of the consent form once I have agreed to participate.

Participant name printed

Participant signature

Date

Name of Person Conducting Informed Consent
Discussion / Witness ³
(Printed)

Signature of Person Conducting Informed Consent
Discussion / Witness

Date

Principal Investigator Signature (if different from above)

Date ⁴

VCU Memo

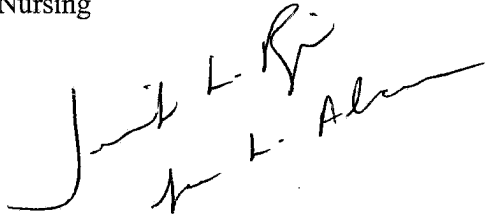
V i r g i n i a C o m m o n w e a l t h U n i v e r s i t y

Office of Research Subjects Protection
BioTechnology Research Park
BioTech One, 800 E. Leigh Street, #114
P.O. Box 980568
Richmond, Virginia 23298-0568
(804) 828-3992
(804) 827-1448 (fax)

DATE: December 20, 2010

TO: Rita H. Pickler, PhD
Family and Community Health Nursing
Box 980567

FROM: Lisa M. Abrams, PhD
Chairperson, VCU IRB Panel B
Box 980568



RE: **VCU IRB #: HM13385**
Title: The Lived Experience of Parents who have a Child with Autism Spectrum Disorder

On December 20, 2010, the following research study was approved by expedited review according to 45 CFR 46.110 Categories 6 and 7. The approval reflects the revisions received in the Office of Research Subjects Protection on December 16, 2010, and December 20, 2010. This approval includes the following items reviewed by this Panel:

RESEARCH APPLICATION/PROPOSAL: None

PROTOCOL (Research Plan): Managing the Needs of Adolescents with Autism Spectrum Disorder: A Parent's Experience, received 12/16/10, version 2

CONSENT/ASSENT (attached):

- Research Subject Information and Consent Form: Managing the Needs of Adolescents with Autism Spectrum Disorder: A Parent's Experience, received 12/6/10, version 1, 3 pages

ADDITIONAL DOCUMENTS (attached):

- Flyer: Participants Needed for Research Study (Appendix A), received 12/16/10, version 2
- Advertisement for Submission to Newspapers (Appendix B), received 12/20/10, version 2
- Confirmation Letter to Participants (Appendix C), received 12/16/10, version 2
- Thank You Letter to Participants (Appendix D), received 12/6/10, version 1

This approval expires on November 30, 2011. Federal Regulations/VCU Policy and Procedures require continuing review prior to continuation of approval past that date. Continuing Review report forms will be mailed to you prior to the scheduled review.

The Primary Reviewer assigned to your research study is Lou Usry, RN. If you have any questions, please contact Ms. Usry at lusry@mcvh-vcu.edu and 828-9229; or you may contact Jennifer Rice, IRB Coordinator, VCU Office of Research Subjects Protection, at jlrice@vcu.edu and 828-3992.

Conditions of Approval:

In order to comply with federal regulations, industry standards, and the terms of this approval, the investigator must (*as applicable*):

1. Conduct the research as described in and required by the Protocol.
2. Obtain informed consent from all subjects without coercion or undue influence, and provide the potential subject sufficient opportunity to consider whether or not to participate (unless Waiver of Consent is specifically approved or research is exempt).
3. Document informed consent using only the most recently dated consent form bearing the VCU IRB "APPROVED" stamp (unless Waiver of Consent is specifically approved).
4. Provide non-English speaking patients with a translation of the approved Consent Form in the research participant's first language. The Panel must approve the translated version.
5. Obtain prior approval from VCU IRB before implementing any changes whatsoever in the approved protocol or consent form, unless such changes are necessary to protect the safety of human research participants (e.g., permanent/temporary change of PI, addition of performance/collaborative sites, request to include newly incarcerated participants or participants that are wards of the state, addition/deletion of participant groups, etc.). Any departure from these approved documents must be reported to the VCU IRB immediately as an Unanticipated Problem (see #7).
6. Monitor all problems (anticipated and unanticipated) associated with risk to research participants or others.
7. Report Unanticipated Problems (UPs), including protocol deviations, following the VCU IRB requirements and timelines detailed in [VCU IRB WPP VIII-7](#):
8. Obtain prior approval from the VCU IRB before use of any advertisement or other material for recruitment of research participants.
9. Promptly report and/or respond to all inquiries by the VCU IRB concerning the conduct of the approved research when so requested.
10. All protocols that administer acute medical treatment to human research participants must have an emergency preparedness plan. Please refer to VCU guidance on <http://www.research.vcu.edu/irb/guidance.htm>.
11. The VCU IRBs operate under the regulatory authorities as described within:
 - a) U.S. Department of Health and Human Services Title 45 CFR 46, Subparts A, B, C, and D (for all research, regardless of source of funding) and related guidance documents.
 - b) U.S. Food and Drug Administration Chapter I of Title 21 CFR 50 and 56 (for FDA regulated research only) and related guidance documents.
 - c) Commonwealth of Virginia Code of Virginia 32.1 Chapter 5.1 Human Research (for all research).

[010507]

RESEARCH SUBJECT INFORMATION AND CONSENT FORM

TITLE: Managing the Healthcare Needs of Adolescents with Autism Spectrum Disorder: A Parent's Experience

VCU IRB NO.: HM13385



This consent form may contain words that you do not understand. Please ask the study staff to explain any words that you do not clearly understand. You may take home an unsigned copy of this consent form to think about or discuss with family or friends before making your decision.

PURPOSE OF THE STUDY

The purpose of this research study is to find out about parents' experiences in managing the healthcare needs of adolescents with Autism Spectrum Disorder (ASD).

You are being asked to participate in this study because you have an adolescent (age 10-18 years) with Autism Spectrum Disorder that requires management of healthcare needs.

DESCRIPTION OF THE STUDY AND YOUR INVOLVEMENT

If you decide to be in this research study, you will be asked to sign this consent form after you have had all your questions answered and understand what will happen to you.

In this study you will be asked to attend one interview session. The session will last no longer than three hours. During the interview, you will be asked to talk about what it is like to manage the healthcare needs of your adolescent with ASD. The interview will be tape recorded so we are sure to get your ideas, but no names will be recorded on the tape. You will be sent the analysis from your interview so that you can review it for accuracy.

RISKS AND DISCOMFORTS

Sometimes talking about experiences causes people to become upset. Some questions about things that have happened in your family may be unpleasant to talk about. You do not have to talk about any subjects you do not want to talk about, and you may leave the interview at any time. If you become upset, the study staff will give you names of counselors to contact to help in dealing with these issues.

BENEFITS TO YOU AND OTHERS

You may not get any direct benefit from this study, but the information we learn from people in this study may help us design better programs for parents of adolescents with autism.

COSTS

There are no costs for participating in this study other than the time you will spend in the interview session.

ALTERNATIVES

The alternative is to not participate in this study.

CONFIDENTIALITY

Potentially identifiable information about you will consist of interview notes and recordings. Data are being collected only for research purposes. Your data will be identified by identification numbers, not names, and stored in a locked research area. There will be no personal identifying information kept about you. The data files will be password protected and deleted within 7 years of completion of the study. Access to all data will be limited to study personnel.

We will not tell anyone the answers you give us; however, information from the study and the consent form signed by you may be looked at or copied for research or legal purposes by Virginia Commonwealth University.

What we find from this study may be presented at meetings or published in papers, but your name will never be used in these presentations or papers.

The interview session will be audio taped, but no names will be recorded. At the beginning of the session, all participants will be asked to use initials only so that no names are recorded. The tapes and the notes will be stored in a locked cabinet. At the completion of the study, the tapes will be destroyed.

VOLUNTARY PARTICIPATION AND WITHDRAWAL

You do not have to participate in this study. If you choose to participate, you may stop at any time without any penalty. You may also choose not to answer particular questions that are asked in the study.

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- the study staff thinks it necessary for your health or safety;
- you have not followed study instructions; or
- administrative reasons require your withdrawal.

QUESTIONS

In the future, you may have questions about your participation in this study. If you have any questions, complaints, or concerns about the research, contact:

Rita H. Pickler, PhD, RN, PNP-BC, FAAN
Endowed Alumni Professor
Family and Community Health Nursing
VCU School of Nursing
1100 East Leigh St.
PO Box 980567
Richmond, VA 23298
Ph: (804) 828-0721

APPROVED

12-20-10 / Lu / JTC www.manaraa.com

rpickler@vcu.edu

If you have any questions about your rights as a participant in this study, you may contact:

Office for Research
Virginia Commonwealth University
800 East Leigh Street, Suite 113
P.O. Box 980568
Richmond, VA 23298
Telephone: 804-827-2157

You may also contact this number for general questions, concerns or complaints about the research. Please call this number if you cannot reach the research team or wish to talk to someone else. Additional information about participation in research studies can be found at <http://www.research.vcu.edu/irb/volunteers.htm>.

CONSENT

I have been given the chance to read this consent form. I understand the information about this study. Questions that I wanted to ask about the study have been answered. My signature says that I am willing to participate in this study. I will receive a copy of the consent form once I have agreed to participate.

Participant name (printed)

Participant signature

Date

Name of Person Conducting Informed Consent
(Printed)

Signature of Person Conducting Informed Consent
Discussion / Witness

Date

Principal Investigator Signature (if different from above)

Date

[Type text]



Appendix A:

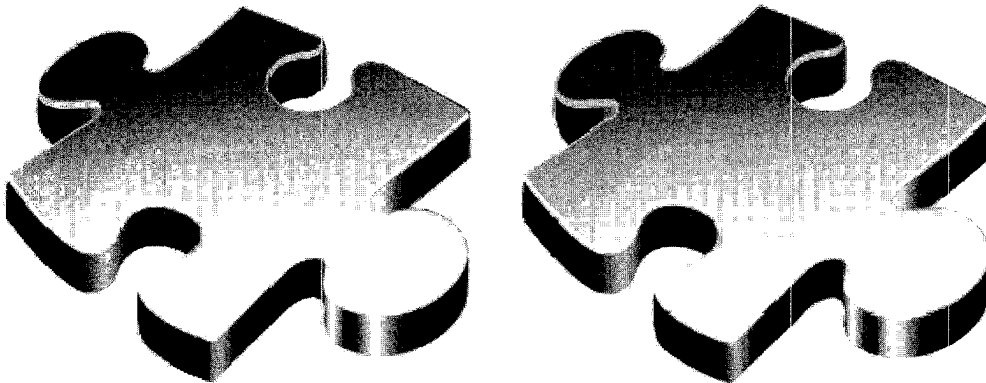
Participants Needed for Research Study

Seeking parents of children ages 10 to 18 with Autism Spectrum Disorder to participate in a research study being conducted as part of a study at Virginia Commonwealth University School of Nursing by Julie Stunk, MS, RN.

The purpose of this study is to examine the experiences of parents who have an adolescent child with Autism Spectrum Disorder.

Participation involves an interview consisting of several open-ended questions. The interview will last no longer than 3 hours and will take place at the James Madison University Institute for Innovation in Health and Human Services. Childcare will not be provided.

If you are interested in participating in the study, please call or email Julie Stunk at 540-564-1728 (strunkja@vcu.edu) or you may contact her advisor, Dr. Rita Pickler at 804-828-0721 (rpickler@vcu.edu).



Appendix B

Advertisement for submission to newspapers

Participants Needed for Research Study



Seeking parents of children ages 10 to 18 with Autism Spectrum Disorder to participate in a research study being conducted as part of a study at Virginia Commonwealth University School of Nursing by Julie Stunk, MS, RN.

The purpose of this study is to examine the experiences of parents who have an adolescent child with Autism Spectrum Disorder.

Participation involves an interview consisting of several open-ended questions. The interview will last no longer than 3 hours and will take place at the James Madison University Institute for Innovation in Health and Human Services. Childcare will not be provided.

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Appendix C: Confirmation Letter to Participants

Date _____



Parent address here

Dear _____

Thank you for your interest in my dissertation research on the experience of managing the healthcare needs of the adolescent with Autism Spectrum Disorder. I value the unique contribution that you can make to my study and I am excited about the possibility of your participation in it. The purpose of this letter is to review what we have already discussed and to provide you a copy of the consent form, which we will sign when we meet.

The research I am doing is a qualitative study in which I am seeking comprehensive descriptions of your experience. In this way I hope to answer my question: "What is the experience of managing the healthcare needs of an adolescent with Autism Spectrum Disorder?"

Through your participation, I hope to understand what it is like to manage the healthcare needs of the adolescent with autism spectrum disorder. You will be asked to recall specific episodes, situations, or events that you experienced in seeking health care for your adolescent. I am seeking vivid, accurate, and comprehensive portrayals of what these experiences were like for you: your thoughts, feelings, and behaviors, as well as situations, events, places, and people connected with your experience.

I value your participation and thank you for the commitment of time, energy, and effort. We are scheduled to meet at the James Madison University Institute for Innovation in Health and Human Services on DATE at TIME. Child care will not be provided. If you have any further questions or if there is a problem with the date and time of our meeting, I can be reached at 540-564-1728. My dissertation advisor, Dr. Rita Pickler, can be reached if needed at 804-828-0721 (rpickler@vcu.edu).

With warm regards,

Julie A. Strunk, RN, MSN

Appendix D: Thank You Letter to Participants

Date _____

Parent Address

Dear _____



Thank you for meeting with me and sharing your parenting experience about managing the health care needs of your adolescent. I appreciate your willingness to share your unique and personal thoughts, feelings, events, and situations.

I have enclosed a summary of my analysis of my interview with you. I would appreciate your review of this analysis. Please ask yourself if this analysis represents your experience of managing the healthcare needs of your adolescent with Autism Spectrum Disorder. After reviewing the analysis, please feel free to add comments, with the enclosed red pen, that would further elaborate your experience(s), or if you prefer we can arrange to meet again and tape record your additions or corrections.

When you have reviewed the analysis and have had an opportunity to make changes and additions, please return it to me in the stamped, addressed envelope.

I greatly value your participation in this research study and your willingness to share your experience. If you have any questions or concerns, do not hesitate to call me at 540-564-1728. You may also call my dissertation advisor, Dr. Rita Pickler, at 804-828-0721, if needed.

With warm regards,

Julie A. Strunk, RN, MSN

VCU Memo

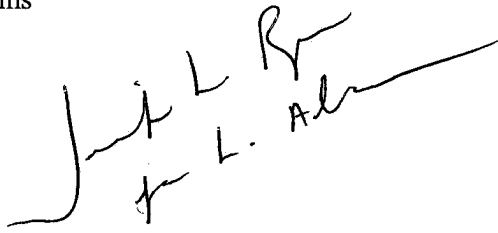
V i r g i n i a C o m m o n w e a l t h U n i v e r s i t y

Office of Research Subjects Protection
BioTechnology Research Park
800 East Leigh Street, Suite 114
P.O. Box 980568
Richmond, Virginia 23298-0568
(804) 827-0868
Fax: (804) 827-1448

DATE: May 5, 2011

TO: Nancy L. McCain, PhD
Adult Health and Nursing Systems
Box 980567

FROM: Lisa M. Abrams, PhD
Chairperson, VCU IRB Panel B
Box 980568



RE: **VCU IRB #: HM13385**
Title: The Lived Experience of Parents who have a Child with Autism Spectrum Disorder

On May 4, 2011, the changes to your research study were approved in accordance with 110 (b) (2). This approval includes the following items reviewed by this Panel:

PROTOCOL (Research Plan): Managing the Healthcare Needs of Adolescents with Autism Spectrum Disorder: A Parent's Experience, received 4/26/11, version 3

CONSENT/ASSENT (attached):

- Research Subject Information and Consent Form: Managing the Healthcare Needs of Adolescents with Autism Spectrum Disorder: A Parent's Experience, received 4/26/11, version 2, 3 pages

ADDITIONAL DOCUMENTS (attached):

- Flyer: Participants Needed for Research Study (Appendix A), received 4/26/11, version 3
- Advertisement for Submission to Newspapers (Appendix B), received 4/26/11, version 3
- Confirmation Letter to Participants (Appendix C), received 4/26/11, version 3
- Thank You Letter to Participants (Appendix D), received 4/26/11, version 2

Please Note: At this time of review, the VCU IRB acknowledges the change in Principal Investigator from Rita Pickler, PhD, to Nancy McCain, PhD.

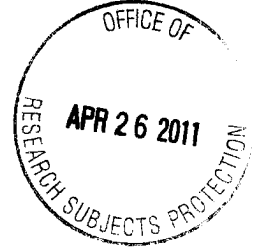
As a reminder, the approval for this study expires on November 30, 2011. Federal Regulations/VCU Policy and Procedures require continuing review prior to continuation of approval past that date. Continuing Review report forms will be mailed to you prior to the scheduled review.

The Primary Reviewer assigned to your research study is Lou Usry, RN. If you have any questions, please contact Ms. Usry at lusry@mcvh-vcu.edu and 828-9229; or you may contact Jennifer Rice, IRB Coordinator, VCU Office of Research Subjects Protection, at jlrice@vcu.edu or 828-3992.

RESEARCH SUBJECT INFORMATION AND CONSENT FORM

TITLE: Managing the Healthcare Needs of Adolescents with Autism Spectrum Disorder: A Parent's Experience

VCU IRB NO.: Hm13385



This consent form may contain words that you do not understand. Please ask the study staff to explain any words that you do not clearly understand. You may take home an unsigned copy of this consent form to think about or discuss with family or friends before making your decision.

PURPOSE OF THE STUDY

The purpose of this research study is to find out about parents' experiences in managing the healthcare needs of adolescents with Autism Spectrum Disorder (ASD).

You are being asked to participate in this study because you have an adolescent (age 10-18 years) with Autism Spectrum Disorder that requires management of healthcare needs.

DESCRIPTION OF THE STUDY AND YOUR INVOLVEMENT

If you decide to be in this research study, you will be asked to sign this consent form after you have had all your questions answered and understand what will happen to you.

In this study you will be asked to attend one interview session. The session will last no longer than three hours. During the interview, you will be asked to talk about what it is like to manage the healthcare needs of your adolescent with ASD. The interview will be tape recorded so we are sure to get your ideas, but no names will be recorded on the tape. You will be sent the analysis from your interview so that you can review it for accuracy.

RISKS AND DISCOMFORTS

Sometimes talking about experiences causes people to become upset. Some questions about things that have happened in your family may be unpleasant to talk about. You do not have to talk about any subjects you do not want to talk about, and you may leave the interview at any time. If you become upset, the study staff will give you names of counselors to contact to help in dealing with these issues.

BENEFITS TO YOU AND OTHERS

You may not get any direct benefit from this study, but the information we learn from people in this study may help us design better programs for parents of adolescents with autism.

COSTS

There are no costs for participating in this study other than the time you will spend in the interview session.

ALTERNATIVES

The alternative is to not participate in this study.

CONFIDENTIALITY

Potentially identifiable information about you will consist of interview notes and recordings. Data are being collected only for research purposes. Your data will be identified by identification numbers, not names, and stored in a locked research area. There will be no personal identifying information kept about you. The data files will be password protected and deleted within 7 years of completion of the study. Access to all data will be limited to study personnel.

We will not tell anyone the answers you give us; however, information from the study and the consent form signed by you may be looked at or copied for research or legal purposes by Virginia Commonwealth University.

What we find from this study may be presented at meetings or published in papers, but your name will never be used in these presentations or papers.

The interview session will be audio taped, but no names will be recorded. At the beginning of the session, all participants will be asked to use initials only so that no names are recorded. The tapes and the notes will be stored in a locked cabinet. At the completion of the study, the tapes will be destroyed.

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QUESTIONS

In the future, you may have questions about your participation in this study. If you have any questions, complaints, or concerns about the research, contact:

Nancy L. McCain, PhD, RN, FAAN
Endowed Alumni Professor
Adult Health and Nursing Systems
VCU School of Nursing
1100 East Leigh St.
PO Box 980567
Richmond, VA 23298
Ph: (804) 828-3444

APPROVED

5-4-11 / L. www.Fanaa.com

nlmccain@vcu.edu

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Virginia Commonwealth University
800 East Leigh Street, Suite 113
P.O. Box 980568
Richmond, VA 23298
Telephone: 804-827-2157

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I have been given the chance to read this consent form. I understand the information about this study. Questions that I wanted to ask about the study have been answered. My signature says that I am willing to participate in this study. I will receive a copy of the consent form once I have agreed to participate.

Participant name (printed)

Participant signature

Date

Name of Person Conducting Informed Consent
(Printed)

Signature of Person Conducting Informed Consent
Discussion / Witness

Date

Principal Investigator Signature (if different from above)

Date

Appendix A:

Participants Needed for Research Study

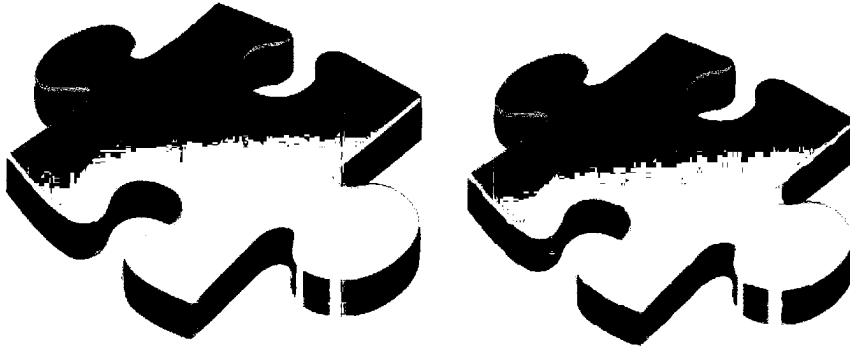


Seeking parents of children ages 10 to 18 with Autism Spectrum Disorder to participate in a research study being conducted as part of a study at Virginia Commonwealth University School of Nursing by Julie Stunk, MS, RN.

The purpose of this study is to examine the experiences of parents who have an adolescent child with Autism Spectrum Disorder.

Participation involves an interview consisting of several open-ended questions. The interview will last no longer than 3 hours and will take place at the James Madison University Institute for Innovation in Health and Human Services. Childcare will not be provided.

If you are interested in participating in the study, please call or email Julie Strunk at 540-564-1728 (strunkja@vcu.edu) or you may contact her advisor, Dr. Nancy McCain at 804-828-3444 (nlmccain@vcu.edu).



Appendix B

Advertisement for submission to newspapers

Participants Needed for Research Study



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Appendix C: Confirmation Letter to Participants

Date _____



Parent address here

Dear _____

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The research I am doing is a qualitative study in which I am seeking comprehensive descriptions of your experience. In this way I hope to answer my question: "What is the experience of managing the healthcare needs of an adolescent with Autism Spectrum Disorder?"

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With warm regards,

Julie A. Strunk, RN, MSN

Appendix D: Thank You Letter to Participants

Date _____

Parent Address

Dear _____

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I have enclosed a summary of my analysis of my interview with you. I would appreciate your review of this analysis. Please ask yourself if this analysis represents your experience of managing the healthcare needs of your adolescent with Autism Spectrum Disorder. After reviewing the analysis, please feel free to add comments, with the enclosed red pen, that would further elaborate your experience(s), or if you prefer we can arrange to meet again and tape record your additions or corrections.

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I greatly value your participation in this research study and your willingness to share your experience. If you have any questions or concerns, do not hesitate to call me at 540-564-1728. You may also call my dissertation advisor Dr. Nancy McCain, at 804-828-3444, if needed.

With warm regards,

Julie A. Strunk, RN, MSN



Full Board
or

James Madison University
HUMAN RESEARCH REVIEW REQUEST

Expedited

Investigators: This form is required for Full Board or Expedited review for all JMU research involving human subjects. If you are eligible for an exemption request, please use the alternate form at:

<http://www.jmu.edu/sponsprog/irb/irbExemptRequest.doc>

FOR IRB USE ONLY:

Protocol Number: IRB- _____

Received: _____

1st Review: _____

2nd Review: _____

3rd Review: _____

Reviewer: _____

Approved

Date: _____

Reviewer: _____

Disapproved

Date: _____

Exempt

Date: _____

External Funding: YES NO If YES, Sponsor(s): _____

Project Title: MANAGING THE HEALTHCARE NEEDS OF ADOLESCENTS WITH AUTISM SPECTRUM DISORDER: A PARENT'S EXPERIENCE

Project Dates: From: 1/26/11 To: 4/15 /11
(Not to exceed 1 yr minus 1 day) MM/DD/YY MM/DD/YY

Minimum Number of Participants 8

Maximum Number of Participants 10

Responsible

Researcher(s): Julie A. Strunk, RN, MSN, PhDc

E-mail: strunkja@jmu.edu

Telephone: 540-564-1728

Department: Nursing

Address 1100 East Leigh Street

(MSC): PO Box 980567

Richmond, VA 23298

Please select:
 Faculty Visiting Adjunct Research Administrator/
(if Applicable): Faculty Faculty Associate Staff Member Undergrad Graduate Student

Research

Advisor: Rita Pickler, RN, PhD

E-mail: rpickler@vcu.edu

Telephone: (804) 828-0721

Department: School of Nursing

Address 1100 East Leigh Street

(MSC): PO Box 980567

Richmond, VA 23298

Investigator: Please respond to the questions below. The IRB will utilize your responses to evaluate your protocol submission.

1. **YES** **NO** Does the James Madison University Institutional Review Board define the project as **research**?

The James Madison University IRB defines "research" as a "systematic investigation designed to develop or contribute to generalizable knowledge." All research involving human participants conducted by James Madison University faculty, staff, and students is subject to IRB review.

2. **YES** **NO** Are the human participants in your study **living** individuals?

"Individuals whose physiologic or behavioral characteristics and responses are the object of study in a research project. Under the federal regulations, human subjects are defined as: living individual(s) about whom an investigator conducting research obtains: (1) data through intervention or interaction with the individual; or (2) identifiable private information."

3. **YES** **NO** Will you obtain data through **intervention** or **interaction** with these individuals?

"Intervention" includes both physical procedures by which data are gathered (e.g., measurement of heart rate or venipuncture) and manipulations of the participant or the participant's environment that are performed for research purposes. "Interaction" includes communication or interpersonal contact between the investigator and participant (e.g., surveying or interviewing).

4. **YES** **NO** Will you obtain **identifiable private information** about these individuals?

"Private information" includes information about behavior that occurs in a context in which an individual can reasonably expect that no observation or recording is taking place, or information provided for specific purposes which the individual can reasonably expect will not be made public (e.g., a

medical record or student record). "Identifiable" means that the identity of the participant may be ascertained by the investigator or associated with the information (e.g., by name, code number, pattern of answers, etc.).

5. YES NO Does the study present **more than minimal risk** to the participants?

"Minimal risk" means that the risks of harm or discomfort anticipated in the proposed research are not greater, considering probability and magnitude, than those ordinarily encountered in daily life or during performance of routine physical or psychological examinations or tests. Note that the concept of risk goes beyond physical risk and includes psychological, emotional, or behavioral risk as well as risks to employability, economic well being, social standing, and risks of civil and criminal liability.

CERTIFICATIONS:

For James Madison University to obtain a Federal Wide Assurance (FWA) with the Office of Human Research Protection (OHRP), U.S. Department of Health & Human Services, **all** research staff working with human participants must sign this form and receive training in ethical guidelines and regulations. "Research staff" is defined as persons who have direct and substantive involvement in proposing, performing, reviewing, or reporting research and includes students fulfilling these roles as well as their faculty advisors. The Office of Sponsored Programs maintains a roster of all researchers who have completed training within the past three years.

Test module at OSP website <http://www.jmu.edu/sponsprog/irb/irbtraining.html>

Name of Researcher(s)	Training Completion Date
Julie A. Strunk	12/8/10
Rita H. Pickler	1/1/11

For additional training interests visit the National Institutes of Health Web Tutorial at: <http://cme.nci.nih.gov/>

By signing below, the Responsible Researcher(s), and the Faculty Advisor (if applicable), certifies that he/she is familiar with the ethical guidelines and regulations regarding the protection of human research participants from research risks. In addition, he/she agrees to abide by all sponsor and university policies and procedures in conducting the research. He/she further certifies that he/she has completed training regarding human participant research ethics within the last three years.

_____ Principal Investigator Signature	_____ Date
_____ Principal Investigator Signature	_____ Date
_____ Principal Investigator Signature	_____ Date
_____ Principal Investigator Signature	_____ Date
_____ Faculty Advisor Signature	_____ Date

Submit an electronic version of your **ENTIRE** protocol to jmu_grants@jmu.edu.
Provide a **SIGNED** hard copy of the Research Review Request Form to:

Following are the components for a complete research protocol. Please use this template to complete your protocol for submission. Each category must be addressed in order to provide the IRB sufficient information to approve the research activity. Please use as much space as you need, but adhere to the overall **10-page limitation**.

For additional detail on each category, see: <http://www.jmu.edu/sponsprog/irb/irbsubmit.html>

Purpose and Objectives:

The chief investigator of this study is a doctoral student at Virginia Commonwealth University and adjunct faculty at James Madison University. This study will fulfill her dissertation requirements.

The aim of this study is to examine the parent's experience of managing the healthcare needs of the adolescent with Autism Spectrum Disorder (ASD). Parenting an adolescent with ASD can be a challenging and unique experience. Autism is considered the fastest growing developmental disability in the nation, affecting one out of every 150 children and is now considered to be the third most common childhood disorder, more common than Down syndrome and childhood diabetes combined (CDC, 2010). It occurs more frequently than childhood cancer, cystic fibrosis, and multiple sclerosis together (Autism Society of America, 2009). An estimated 1.5 million individuals in the U.S. and tens of millions worldwide are affected by autism and government statistics suggest the prevalence rate of autism is increasing 10-17 percent annually (CDC, 2010). There is no established explanation for this increase, although improved diagnosis and environmental influences are two reasons often cited.

After performing an integrative review on the perceptions of parents of children with ASD, it was found that two major themes emerged: stress and the need for social support. No studies were found which reflected the parent's perception or experience of managing the healthcare needs of the adolescent with ASD. While the profession of nursing has had a long history in the care and advocacy of vulnerable populations, including parents of children with disabilities, no articles were found in the current nursing literature that address a parent's perception of meeting the health care needs of the adolescent who has autism. Evidence-based nursing practice dictates the use of applying best practices to any decisions involving the care of individual clients. This includes ensuring delivery of healthcare services to the most vulnerable populations, which would encompass parents of adolescents with ASD. With the increasing numbers of children being diagnosed with ASD and with autism becoming a prominent topic in the health and educational fields, the importance of exploring the lived experience of those parents managing the healthcare needs of the ASD adolescent cannot be over stated. It is only from hearing their individual stories that researchers can discover how to work with and provide services for these individuals.

Procedures/Research Design/Methodology/Timeframe:

Through the use of Moustakas' phenomenological approach, there will be a better understanding of the lived experience of parents who manage their ASD adolescent's healthcare needs and to allow the investigator to understand the meaning of their experience. This is important because there have been no other studies examining this issue. According to Moustakas, the nature of the lived experience allows the individual to focus on seeing, listening, touching, and thinking on what that experience is in its essences (Moustakas, 1994). The researcher can examine the experience for what it is, under what conditions it occurs, from what frame of reference, and what its possible meanings are (Moustakas, 1994). By turning to the lived experience, the researcher can describe in detail the whole account of an issue, problem, situation, or experience, using qualities and properties from specific contexts or perspectives, so that the experience takes on a vivid or essential meaning, a clear picture of what is (Moustakas, 1994). Phenomenological studies do not require a specific number of participants. More importantly, phenomenological studies need to have enough participants to adequately explore the phenomenon being studied. Creswell (1998) recommended that the phenomenologist interview a small number of individuals, no more than 10. With this in mind, 10 parents (mother, father, or both) of adolescents (between the ages of 10 to 18) with Autism Spectrum Disorder will be interviewed for this study. Moustakas (1994) recommended participants be selected according to two criteria:

(a) they are experiencing the phenomenon being studied, and (b) they are willing to participate in the study and willing to be interviewed. Parents will be purposefully chosen to participate in this study because of their experience in managing the healthcare needs of an adolescent who has ASD and their willingness to share their experience.

Participants will be recruited by direct solicitation through the use of printed flyers publicizing the proposed study (see flyer in Appendix A). These flyers will be posted at the James Madison University Department of Nursing, Harrisonburg, Virginia, Kluge Children's Rehabilitation Center, Charlottesville, Virginia, and Institute for Innovation in Health and Human Services, Harrisonburg, Virginia. A flyer will also be sent to the Shenandoah Valley Autism Partnership at svap@valleyautism.org and James Madison University T/TAC at sally.chappel@gmail.com. An advertisement will be posted in the Daily News Record, the Staunton News Leader, and the Valley Banner to run for two consecutive days. Prospective participants will contact the PI or student investigator. Following that contact, at which time the study will be explained to the prospective participant, the prospective participant will be sent a letter explaining the nature of the study along with a consent form. The letter will include a description of the study, the purpose, and procedures as well as confirmation of an appointment time that suits the participant's schedule. The consent form will be collected at the time of the interview. The interviews will take place in a quiet office at the James Madison University Institute for Innovation in Health and Human Services. Participants will be expected to provide their own childcare as interviews will take place without their children being present. Each interview will be audiotaped. The length of interviews will vary depending on the amount of information that each participant is willing to share; interviews will not exceed three hours. Inclusion criteria include: (a) must be the parent or a child between the ages of 10 and 18 who has a diagnosis of Autism Spectrum Disorder and who has guardianship the child; (b) the parent/s must be able to speak and read English; and (c) the child must have at least one on-going health care need in addition to ADS. Exclusion criteria include: (a) parents who are not the primary caregivers of the child; (b) parents of children with ASD who were adopted.

The interview will be an interactive process between the participant and the researcher. The questions will be open ended and follow-up questions will be used to assist in clarifying and understanding the information presented. A general guide of questions will include asking participants what it is like managing the healthcare needs of an adolescent with ASD and how this affects them and those in their immediate family.

Each participant will be informed that the information will be shared with the public by a written manuscript which will be submitted to a peer-reviewed journal. Participants will be assured that all identifying information will be removed. The student researcher will be responsible for transcribing all data from the audiotapes. Transcripts will be stored at the VCU School of Nursing as part of the VCU IRB data collection policies. The student researcher will use one working copy of the transcripts for analysis.

The proposed project is not a clinical trial. However, the student investigator is available 24 hours a day by cell phone or home phone; these numbers are provided to participants. The student investigator will meet monthly with the PI (dissertation chair) to monitor for safety issues, particularly parent distress. In addition, the study process will be reviewed for unexpected occurrences or alterations. Any changes will be examined for their relationship to the project protocol. Reports of these chair meetings will be reviewed at the full progress meetings of the Dissertation Committee.

Because the planned project involves minimal risk, no adverse events are expected to occur as a direct result of participant participation. However, should any event occur that might be related to study participation, the study investigator will assume responsibility for notification of the designated care providers and any referral for recommended treatment, as well as notification of the VCU IRB. Adverse event reporting forms and procedures are available on-line at: <http://www.orsp.vcu.edu/irb>. As part of the requirements of the JMU IRB, the investigator would also notify them.

Time frame of study will take place from January 26, 2011 to April 15, 2011.

Data Analysis:

Data will be analyzed using Moustakas' (1994) method of analysis of phenomenological data. This method will include the following: horizontalization of participants' statements (separating statements that pertain to the phenomenon and those that do not), reduction and elimination of data (looking for statements that contain a moment of experience necessary for understanding the lived experience and the ability of the statement to be labeled), clustering and thematizing invariant constituents (grouping statements into core themes), validation of invariant constituents (checking themes against the transcript of the participant to ensure that the statements match and that the statements express what the participant conveys), individual textural descriptions (explanation of the core themes as they apply to a particular participant's lived experience – participants will be given a copy of their textural description to read to ensure accuracy), and individual structural descriptions (looking at underlying feelings and thoughts experienced by the participants). The final two steps will include creating a textural-structural description of the meanings and essence of the experiences for each participant and developing a composite description of the meanings and essences of the experience for the group as a whole.

This study will strive to establish trustworthiness by including credibility, transferability, dependability, and confirmability. Credibility is enhanced by the following techniques: (a) prolonged engagement, (b) triangulation, (c) peer debriefing, (d) negative case analysis, (e) referential adequacy, and (f) member checking. This study will maximize credibility by using three of these strategies: prolonged engagement, peer debriefing, and member checking.

Prolonged engagement requires that the researcher use extended time to reflect on journals and field notes and test how their perceptions of the experience have changed over that extended time frame. According to Guba (1981), researchers need to be able to show that sufficient time was spent in the field in order to justify their characterizations of the experience. In this case, the student researcher will spend at least three hours with each participant in the interview session.

Peer debriefing requires that the researcher select one or more peers who will serve as a guide and discuss interpretations and concerns with those colleagues. According to Guba (1981), it is important for researchers to regularly detach themselves from the field, and to seek counsel from other professionals who are willing to perform the debriefing function. In this case, the student researcher has a doctoral colleague who knowledgeable of the approach and is willing to read and discuss any interpretations or concerns that are found.

Member checking requires that the researcher obtain feedback from the research participants (Lincoln & Guba, 1985). This feedback is particularly useful when the analysis and interpretation have been made and conclusions have been drawn (Tutty, Rothery, & Grinnell, 1996; Guba, 1981). In this case, the student researcher will invite the participants to read their composite structural/textural stories in order to allow for any changes that need to be made and to affirm that what has been written is an accurate portrayal of their experiences. If requested by the participant, a second interview will occur.

The responsibility for transferability falls not only on the original researcher but on the person seeking to apply the information (Lincoln and Guba, 1985). The prospective study may have transferability to other parents who manage the healthcare needs of their adolescent with ASD; ultimately, it is up to the individual seeking the application to determine if the data is applicable. The researcher can facilitate transferability by providing thick descriptions from the participants' words and providing rich narratives of their experiences. Dependability will be achieved by maintaining an inquiry audit (Lincoln and Guba, 1985). This audit will consist of examining the data-collection process and the data process by keeping a reflexive journal, maintaining a notebook with transcripts and the researcher's reactions and thoughts, and consulting an experienced and qualified outside expert to review or audit the consistency of the research process.

To enhance confirmability an audit-trail record will be created during each phase of the data collection and data analysis process (Lincoln and Guba, 1985). It will consist of the following: (1) raw data, interview, audiotapes, transcripts; (2) data-analysis materials such as write-ups, interview notes, results, findings, interpretations, themes, definitions; (3) all process notes describing methodology and trustworthiness; and (4) all

materials concerning expectations, predictions and intentions, question development and data collection. At the completion of this study, the principle investigator will examine the audit trail and verify whether procedures were followed and interpretations were reasonable (Guba, 1981).

The final technique is reflexive journaling. The researcher will maintain a daily journal that includes biases, thoughts, reflections, daily schedules, and a methodological log. It is important to recognize that a reflective level of self-awareness and self-consciousness is required to begin to capture the perspectives through which the world is viewed and that it may be impossible to take hold of the unconscious filters through which we experience events (Bell & Newby, 1977; Bell & Roberts, 1984; Mauthner & Doucet, 2003).

Confidentiality of participant data is the primary safety-related issue in this study. Participants' identities will be protected. Each data record will be assigned an arbitrary code number by the student investigator and then identifying information will be removed from the data record and attached to the consent form, which will be kept in a locked file accessible only by the study personnel.

Study participants and information will only be accessible to the student investigator and the PI who will maintain participant privacy. Each study visit will be conducted in a private room to ensure participants' privacy.

Reporting Procedures:

While the profession of nursing has had a long history in the care and advocacy of vulnerable populations, including parents of children with disabilities, no articles have been found in the current nursing literature that address the experience of parents who manage the healthcare needs of an adolescent with autism spectrum disorder. Evidence-based nursing practice must conscientiously use the current best evidence in making decisions about the care of individual clients and the delivery of healthcare services to the most vulnerable, including parents of adolescents who have an autism spectrum disorder.

The overall goals of this project are to examine the perceptions of parents of adolescents with ASD on managing the healthcare needs of their children and to strive to understand the meaning of that experience. Information gained in this study will be written up in manuscript form and then submitted to a peer-reviewed journal.

The student researcher will invite the participants to read their composite structural/textural stories in order to allow for any changes that need to be made and to affirm that what has been written is an accurate portrayal of their experiences. If requested by the participant, a second interview will occur.

Experience of the researcher (and advisor, if student):

The student researcher has completed the required plan of study for the VCU School of Nursing Doctoral program. The PI will provide any necessary training to the study investigator as a function of the dissertation review process. Please see the attached CVs for the student investigator and the advisor/primary investigator.

Additional Attachments as applicable:

- Consent forms
- Letters of permission
- Cover letter(s)
- Questionnaire
- Tests
- Additional attachments relevant to the study

RESEARCH SUBJECT INFORMATION AND CONSENT FORM

TITLE: Managing the Healthcare Needs of Adolescents with Autism Spectrum Disorder: A Parent's Experience

VCU IRB NO.:

JMU IRB NO.:

This consent form may contain words that you do not understand. Please ask the study staff to explain any words that you do not clearly understand. You may take home an unsigned copy of this consent form to think about or discuss with family or friends before making your decision.

The person conducting this study, Julie A. Strunk, is a doctoral student at Virginia Commonwealth University and adjunct faculty at James Madison University. This study will fulfill her dissertation requirements.

PURPOSE OF THE STUDY

The purpose of this research study is to find out about parents' experiences in managing the healthcare needs of adolescents with Autism Spectrum Disorder (ASD).

You are being asked to participate in this study because you have an adolescent (age 10-18 years) with Autism Spectrum Disorder that requires management of healthcare needs.

DESCRIPTION OF THE STUDY AND YOUR INVOLVEMENT

If you decide to be in this research study, you will be asked to sign this consent form after you have had all your questions answered and understand what will happen to you.

In this study you will be asked to attend one interview session. The session will last no longer than three hours. During the interview, you will be asked to talk about what it is like to manage the healthcare needs of your adolescent with ASD. The interview will be tape recorded so we are sure to get your ideas, but no names will be recorded on the tape. You will be sent the analysis from your interview so that you can review it for accuracy.

RISKS AND DISCOMFORTS

Sometimes talking about experiences causes people to become upset. Some questions about things that have happened in your family may be unpleasant to talk about. You do not have to talk about any subjects you do not want to talk about, and you may leave the interview at any time. If you become upset, the study staff will give you names of counselors to contact to help in dealing with these issues.

BENEFITS TO YOU AND OTHERS

You may not get any direct benefit from this study, but the information we learn from people in this study may help us design better programs for parents of adolescents with autism.

COSTS

There are no costs for participating in this study other than the time you will spend in the interview session, however the approximate time for participation will be no longer than 3 hours.

ALTERNATIVES

The alternative is to not participate in this study.

CONFIDENTIALITY

Potentially identifiable information about you will consist of interview notes and recordings. Data are being collected only for research purposes. Your data will be identified by identification numbers, not names, and stored in a locked research area. There will be no personal identifying information kept about you. The data files will be password protected and deleted within 7 years of completion of the study. Access to all data will be limited to study personnel.

We will not tell anyone the answers you give us; however, information from the study and the consent form signed by you may be looked at or copied for research or legal purposes by Virginia Commonwealth University and James Madison University.

What we find from this study may be presented at meetings or published in papers, but your name will never be used in these presentations or papers.

The interview session will be audio taped, but no names will be recorded. At the beginning of the session, all participants will be asked to use initials only so that no names are recorded. The tapes and the notes will be stored in a locked cabinet. At the completion of the study, the tapes will be destroyed.

VOLUNTARY PARTICIPATION AND WITHDRAWAL

You do not have to participate in this study. If you choose to participate, you may stop at any time without any penalty. You may also choose not to answer particular questions that are asked in the study.

Your participation in this study may be stopped at any time by the study staff without your consent. The reasons might include:

- the study staff thinks it necessary for your health or safety;
- you have not followed study instructions; or
- administrative reasons require your withdrawal.

QUESTIONS

In the future, you may have questions about your participation in this study. If you have any questions, complaints, or concerns about the research, contact:

Rita H. Pickler, PhD, RN, PNP-BC, FAAN
Endowed Alumni Professor
Family and Community Health Nursing
VCU School of Nursing
1100 East Leigh St.
PO Box 980567
Richmond, VA 23298
Ph: (804) 828-0721
rpickler@vcu.edu

If you have any questions about your rights as a participant in this study, you may contact:

Office for Research
Virginia Commonwealth University
800 East Leigh Street, Suite 113
P.O. Box 980568
Richmond, VA 23298
Telephone: 804-827-2157

Dr. David Cockley
Chair, Institutional Review Board
James Madison University
(540) 568-2834
cocklede@jmu.edu

You may also contact this number for general questions, concerns or complaints about the research. Please call this number if you cannot reach the research team or wish to talk to someone else. Additional information about participation in research studies can be found at <http://www.research.vcu.edu/irb/volunteers.htm> or <http://www.jmu.edu/sponsprog/contact.html>.

CONSENT

I have been given the chance to read this consent form. I understand the information about this study. Questions that I wanted to ask about the study have been answered. My signature says that I am willing to participate in this study. I will receive a copy of the consent form once I have agreed to participate.

Participant name (printed)

Participant signature

Name of Person Conducting Informed Consent
(Printed)

Signature of Person Conducting Informed Consent Discussion / Witness	Date
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Principal Investigator Signature (if different from above)	Date
--	------

Interview Questions

The interview will be an interactive process between the participant and the researcher. The questions will be open-ended and follow-up questions will be used to assist in clarifying and understanding the information presented. A general guide of questions will include asking participants what it is like managing the healthcare needs of an adolescent with ASD and how this affects them and those in their immediate family. Examples of questions will include:

1. Will you tell me what it is like for you to be the parent of an adolescent who has autism?
2. How have you changed as a parent since your child entered adolescence?
3. Will you tell me about your child's health care needs?
4. How do you manage these needs?
5. Who helps you manage those needs?

References

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- Bell, C. & Newby, H. (Eds.). (1977). *Doing Sociological Research*. London: Allen & Unwin.
- Bell, C. & Roberts, H. (Eds.). (1984). *Social Researching: Politics, Problems, Practice*. London: Routledge and Kegan Paul.
- Centers for Disease Control and Prevention. (2010). Autism spectrum disorders (ASDs). Retrieved from <http://www.cdc.gov/ncbddd/autism/index.html>
- Creswell, J. W. (1998). *Qualitative Inquiry and Research Design; Choosing Among Five Traditions*. London, New Delhi, Thousand Oaks, Sage Publications
- Guba, E. G. (1981). Criteria for assessing the trustworthiness of naturalistic inquiries, *Educational Communication and Technology Journal*, 29 (2), 75-91.
- Lincoln, Y.S. & Guba, E.G. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage Publications.
- Mauthner, N.S. & Doucet, A. (2003). Reflexive accounts and accounts of reflexivity in qualitative data analysis. *Sociology*, 37(3), 413-431. Doi: 10.1177/00380385030373002
- Moustakas, C. (1994). *Phenomenological research methods*. Thousand Oaks, CA: Sage.
- Tutty, L.M., Rothery, M.A., & Grinnell, R.M., Jr. (1996). *Qualitative research for social workers*. Neecham Heights, MA: Allyn & Bacon.

Curriculum Vitae

CONTACT INFORMATION

Julie A. Strunk, RN, MSN
855 Wild Cherry Lane
Harrisonburg, Virginia 22801
(540) 564-1728
(540) 435-9313
strunkja@gmail.com

EDUCATION

James Madison University, Harrisonburg, Virginia
B.S. Health Science
May 1979

Florida Community College Jacksonville, Jacksonville, Florida
A.S. Nursing
December 1981

James Madison University, Harrisonburg, Virginia
B.S. Nursing
May 2007

James Madison University, Harrisonburg, Virginia
M.S. Nursing
May 2008
Directed Study – Grant Proposal on Fighting Childhood Obesity

Virginia Commonwealth University, Richmond, Virginia
PhD Nursing
August 2009 – present
Dissertation – The Healthcare Needs of Adolescents with Autism Spectrum Disorder: The Parent's Experience

EMPLOYMENT HISTORY

Parish Nurse, First Baptist Church, Jacksonville, Florida
1984-1990

Staff RN, Rockingham Memorial Hospital, Harrisonburg, Virginia
1990-1993

Special Education Teaching Assistant, Harrisonburg City Schools, Harrisonburg, Virginia
1993-1999

School Nurse, Harrisonburg City Schools, Harrisonburg, Virginia
1999-2006

Adjunct faculty, James Madison University School of Nursing, Harrisonburg, Virginia 2008 – present

Adjunct faculty, Virginia Commonwealth University School of Nursing, Richmond, Virginia
2009 – present

RESEARCH SKILLS

Extensive knowledge of SPSS, SAS, JMP, and Minitab

PROFESSIONAL EXPERIENCE

Pediatric clinical instructor, James Madison University School of Nursing, Harrisonburg, Virginia
2008 – present

Instructor, Information Literacy in Health Care, Virginia Commonwealth School of Nursing,
Richmond, Virginia
2009 – present

Teaching Assistant, Nursing of Adults, Virginia Commonwealth School of Nursing, Richmond,
Virginia
2010

Instructor, Special Topics in HHS SP10 (Autism Spectrum Disorders), James Madison
University, Harrisonburg, Virginia
2010

Clinical instructor, Technologies of Nursing Practice, Virginia Commonwealth School of Nursing,
Richmond, Virginia
Summer 2010

Clinical Lab Instructor, Nursing of Women, Virginia Commonwealth School of Nursing, Richmond,
Virginia
Fall 2010

PUBLICATIONS

Strunk, J.A. (2008). The effects of school-based health clinics on teenage pregnancy and parenting outcomes: an integral literature review. *The Journal of School Nursing*, 24(1), 13-20.

Strunk, J.A. (2009). School nurses' knowledge of autism spectrum disorders. *The Journal of School Nursing*, 25(6), 445-452.

Strunk, J.A. and Rocchiccioli, J.T. (2010). Meningococcal meningitis: an emerging infectious disease. *Journal of Community Health Nursing*, 27(1), 51-58.

Strunk, J.A. (2010). Respite care for families of special needs children: a systematic review. *Journal of Developmental and Physical Disabilities*, 22(1), 1-16.

Phillips-Pula, L, Strunk, J.A., & Pickler, R. (2010). Understanding phenomenological approaches to data analysis. *Journal of Pediatric Health Care* (to be published in the Jan/Feb 2011 issue).

PRESENTATIONS

Strunk, J.A. (2008). Getting to the Heart of the Matter. Presented at Pi Mu Day at James Madison University

Strunk, J.A. (2008). School Nurses Working Knowledge of Children with Autism Spectrum Disorders. Presented at the School Health Institute at Longwood College

Strunk, J.A. (2008). Eating Patterns in School Age Children and Their Impact on Childhood Obesity. Presented at the Institute of Health in Malta

Strunk, J.A. (2008). Eating Patterns in School Age Children and Their Impact on Childhood Obesity. Poster presentation at James Madison University

Strunk, J.A. (2009). Maternal Well-being and Preterm Infant Outcomes. Poster presentation at James Madison University

Strunk, J.A. (2009). Maternal Well-being and Preterm Infant Outcomes. Poster presentation at SNRS in Austin, Texas

Strunk, J.A. (2010). Maternal Well-being and Preterm Infant Outcomes. Poster presentation at Virginia Commonwealth University

GRANTS AND FELLOWSHIPS

RMH Foundation (Getting to the Heart of the Matter)

AWARDS AND HONORS

Member Sigma Theta Tau Honor Society

Golden Key International Honor Society

Vida Huber Spirit of Nursing Award

PROFESSIONAL MEMBERSHIPS

Pregnancy Prevention Coalition Board Member

National Association of School Nurses

Virginia Association of School Nurses

Sigma Theta Tau Honor Society

National League of Nurses

National Institute of Nursing Research

National Association of Palliative Care Nurses

American Association of Nurses

BIOGRAPHICAL SKETCH

Provide the following information for the key personnel and other significant contributors in the order listed on Form Page 2.
Follow this format for each person. **DO NOT EXCEED FOUR PAGES.**

NAME Pickler, Rita H.		POSITION TITLE Professor, Family and Community Health Nursing Acting Associate Dean for Research and Scholarship	
eRA COMMONS USER NAME rpickler			
EDUCATION/TRAINING <i>(Begin with baccalaureate or other initial professional education, such as nursing, and include postdoctoral training.)</i>			
INSTITUTION AND LOCATION	DEGREE <i>(if applicable)</i>	YEAR(s)	FIELD OF STUDY
UNC-Greensboro, Greensboro NC	BSN	1979	Nursing
UNC-Greensboro, Greensboro NC	MSN	1981	Nursing
University of Virginia, Charlottesville VA	PhD	1990	Nursing
Virginia Commonwealth University	PM-Cert	1998	Nursing-PNP

A. Positions and Honors. List in chronological order previous positions, concluding with your present position. List any honors. Include present membership on any Federal Government public advisory committee.

1979 -1980	Staff Nurse	Intensive Care Nursery, NC Baptist Hospital, Winston-Salem, NC
1981 -1983	Instructor	Department of Nursing, Virginia State University, Petersburg, VA
1983 -1984	Assistant Professor	Department of Nursing, Virginia State University, Petersburg, VA
1984 -1986	Instructor	Maternal Child Nursing, School of Nursing, Virginia Commonwealth University (VCU), Richmond, VA
1990 -1994	Assistant Professor Collateral Track	Maternal Child Nursing, School of Nursing, VCU, Richmond, VA
1994 -1997	Assistant Professor Tenure Eligible	Maternal Child Nursing, School of Nursing, VCU, Richmond, VA
1997-2006	Associate Professor Tenured	Maternal Child Nursing, School of Nursing, VCU, Richmond, VA
2006- present	Professor, Tenured	Family and Community Health Nursing (formerly Maternal Child Nursing), School of Nursing, VCU, Richmond, VA
2009- present	Nursing Alumni Endowed Professor	School of Nursing
2003-2004	Interim Chair	Maternal Child Nursing, School of Nursing, VCU, Richmond, VA
2004-2009	Chair	Family and Community Health Nursing (formerly Maternal Child Nursing), School of Nursing, VCU, Richmond, VA
2009-2010	Acting Associate Dean for Research and Scholarship	School of Nursing
2007- present	Mentor	Academy of Mentors, Center for Clinical and Translational Research, VCU, Richmond, VA

2007- present Mentor

Building Interdisciplinary Research Careers in Women's Health (BIRCWH). Funded by the National Institutes of Health

Other Experience

1998-2010
2007-2010

Pediatric Nurse Practitioner, Fan Free Clinic, Richmond, VA
CHiLD Clinic, NICU Follow-up, Richmond, VA

Honors

1979 Inducted, Sigma Theta Tau
1998 Nursing Distinguished Alumni Award, School of Nursing, University of North Carolina at Greensboro
2000 Alumni Star, School of Nursing, Virginia Commonwealth University
2002 University Alumna Distinguished Service Award, University of North Carolina at Greensboro
2002 Mabel Montgomery Award, School of Nursing, Virginia Commonwealth University
2003 Shining Star, Nurse Practitioner of the Year, Fan Free Clinic, Richmond, VA
2004 Phi Kappa Phi Honor Society
2008 Fellow, American Academy of Nursing
2009 Award for Excellence in Research, Association of Women's Health, Obstetric, and Neonatal Nursing (AWHONN)

Membership on Review Panels

October 2003, February 2004, June 2004 Ad Hoc Member, Nursing Science: Children and Families Study Section, Center for Scientific Review, National Institutes of Health

July, 2004-June, 2007 Chartered Member, Nursing Science Children and Families Study Section, Center for Scientific Review, National Institutes of Health

July 2007 Chair, Special Emphasis Panel/Scientific Review Group ZNR1 REV-B (04), P20 & P30 Applications, National Institute of Nursing Research, National Institutes of Health

October 2007 Member, Special Emphasis Panel/Scientific Review Group ZRG1 HOP-E (11), Center for Scientific Review, National Institutes of Health, SBIR applications

October 2008 Ad Hoc Member, NRRC 43, Review Panel, NINR

July, 2007-June, 2010 American Nurses Foundation Research Review Committee

October 2008, February 2009 Ad Hoc Member, NRRC, Review Panel NINR

February 2009 Member, Special Emphasis Panel/Scientific Review Group 2009/05 ZRG1 HOP-T (50) M: Using System Science Methodologies to Protect and Improve Population Health

June 2009 Center for Scientific Review, National Institutes of Health, ZRG1 HDM-G Editorial Panel 3 and ZRG1 HDM-P Editorial Panel 26, June 2009

July 2009 Chair, Special Emphasis Panel/Scientific Review Group ZNR1 REV-Y, P30 Faculty Development Applications Member, NINR, Initial Review

July 2009-June 2013 Group (NRRC)

October 2009, 2010 NINR, Special Emphasis Panel /Scientific Review Group ZNR1 (T32 applications),

B. Selected peer-reviewed publications (in chronological order).

1. Pickler, R.H., Higgins, K.E., & Crummette, B.D. (1993). The effect of nonnutritive sucking on bottle feeding stress in preterm infants. *Journal of Obstetric, Gynecologic and Neonatal Nursing*, 22(3), 230-234.
2. Pickler, R.H. (1993). Premature infant-nurse caregiver interaction. *Western Journal of Nursing Research*, 15(5), 548-567.
3. Pickler, R.H., & Terrell, B.R. (1994). Nonnutritive sucking and necrotizing enterocolitis. *Neonatal Network*, 13(8), 15-18.
4. Pickler, R.H., & Frankel, H. (1995). The effect of nonnutritive sucking on preterm infants' behavioral organization and feeding performance. *Neonatal Network*, 14(2), 83.
5. Pickler, R.H., Frankel, H.B., & Walsh, K.M., Thompson, N. (1996). Effects of nonnutritive sucking on behavioral organization and feeding performance in preterm infants. *Nursing Research*, 45(3), 132-135.
6. Pickler, R.H., & Reyna, B.A. (1996). Advanced practice nursing in the care of the high-risk infant. *Journal of Perinatal and Neonatal Nursing*, 10(1), 46-53.
7. Pickler, R.H., Mauck, A.G., & Geldmaker, B.G. (1997). Bottle feeding histories of preterm infants. *Journal of Obstetric, Gynecologic and Neonatal Nursing*, 26, 414-420.
8. Thompson, N., Pickler, R.H., Munro, C., & Shotwell, J. (1997). Contamination in expressed breast milk. *Journal of Human Lactation*, 13, 127-130.
9. Younger, J.B., Kendell, M J., & Pickler, R.H. (1997). Mastery of stress in mothers of preterm infants. *Journal of the Society of Pediatric Nurses*, 2(1), 29-35.
10. Tarr, J., & Pickler, R.H. (1999). Becoming a cancer patient: A study of families of children with ALL. *Journal of Pediatric Oncology Nursing*, 16(1), 44-50.
11. Pickler, R.H. (2001). Nonnutritive sucking. In M. Craft-Rosenberg & J. Denehy (Eds.). *Nursing interventions for childbearing and childrearing families* (pp.139-149). Thousand Oaks, CA: SAGE Publications.
12. Pickler, R.H., & Reyna, B.A. (2003). A descriptive study of bottle feeding opportunities in preterm infants. *Advances in Neonatal Care*, 3(3), 139-146.
13. Pickler, R.H. (2004). A model of feeding readiness for preterm infants. *Neonatal Intensive Care: The Journal of Perinatology-Neonatology*, 17(4), 31-36.
14. Pickler, R.H., & Reyna, B.A. (2004). Effects of nonnutritive sucking on nutritive sucking, breathing, and behavior during bottle feedings of preterm infants. *Advances in Neonatal Care*, 4, 226-234.
15. Crosson, D.D., & Pickler, R.H. (2004). An integrated review of the literature on demand feeding in preterm infants. *Advances in Neonatal Care*, 4, 216-225.
16. Terathongkum, S., & Pickler, R.H. (2004). Heart rate variability, hypertension and relaxation. *Journal of Vascular Nursing*, 22(3), 78-82.
17. Thompson, A., Pickler, R.H., & Reyna, B.A. (2005). Clinical coordination of research. *Applied Nursing Research*, 18, 102-105.
18. Pickler, R.H., Best, A.M., Reyna, B.A., Wetzel, P.A., & Gutcher, G.R. (2005). Prediction of feeding performance in preterm infants. *Newborn and Infant Nursing Reviews*, 5, 116-123.
19. Boonmee, J., & Pickler, R.H. (2005) Transition of preterm infants from hospital to home. *Neonatal Intensive Care*, 18(8), 22-25.
20. Grap, M.J., Pickler, R.H., & Munro, C.M. (2006). Observation of behavior in sedated, mechanically ventilated children. *Pediatric Nursing*, 32(2), 216-220.
21. Pickler, R.H., Chiaranai, C., & Reyna, B.A. (2006). Relationship of the first suck burst to feeding outcomes in preterm infants. *Journal of Perinatal and Neonatal Nursing*, 20, 155-160.
22. Reyna, B.A., Pickler, R.H., & Thompson, A. (2006). Mother's experiences feeding their preterm infants after discharge. *Advances in Neonatal Care*, 6, 333-340.
23. Pickler, R.H., Best, A.M., Reyna, B.A., Wetzel, P.A., & Gutcher, G.G. (2006). Changes in nutritive sucking in preterm infants. *Journal of Perinatology*, 26, 693-699.

24. Reyna, B.A., Pickler, R.H., & Thompson, A. (2006). A descriptive study of mother's experiences feeding their preterm infants after discharge. *Advances in Neonatal Care*, 6, 333-340.
25. Amankwaa, L., Pickler, R.H., & Boonmee, J. (2007). Maternal responsiveness in mothers of preterm infants. *Newborn and Infant Nursing Reviews*, 7, 25-30.
26. Amankwaa, L., & Pickler, R.H. (2007). Measuring maternal responsiveness. *The Association for Black Nursing Faculty Journal*, 18(1), 4-15.
27. Pickler, R.H., Best, A.M., & Crosson, D.D. (2008). The effect of feeding experience on clinical outcomes in preterm infants. *Journal of Perinatology*. 29, 124-129.
28. Reyna, B.A., & Pickler, R.H. (2009). Mother-infant synchrony. *Journal of Obstetric, Gynecologic, and Neonatal Nursing*, 38, 470-477.
29. Lyon, D., Howland, L., Cheng, C., Pickler, R.H., Rattican, D., Brown, L., McGrath, J., & Jallo, N. (2010). *Integrated review of cytokines in maternal, cord, and newborn blood: part I associations with preterm birth. Biological Research for Nursing*. Epub ahead of print.
30. Pickler, R.H., Brown, L., McGrath, J., Lyon, D., Rattican, D., Howland, L., Cheng, C., & Jallo, N. (2010). *Integrated review of cytokines in maternal, cord, and newborn blood: part II--associations with early infection and increased risk of neurologic damage in preterm infants. Biological Research for Nursing*. Epub ahead of print.
31. Cheng, C., & Pickler, R.H. (2009). Maternal psychological well-being and salivary cortisol in late pregnancy and early postpartum. *Stress and Health*, Published online in Wiley InterScience (www.interscience.wiley.com).
32. Cheng, C., & Pickler, R.H. (2009). Effects of stress and social support on postpartum health of Chinese mothers in the United States. *Research in Nursing and Health*. 32, 582-591.
33. Howland, L.C., Pickler, R.H., McCain, N.L., Glaser, D., & Lewis, M. (In Press). Exploring biobehavioral outcomes in mothers of preterm infants. *MCN The Journal of Maternal Child Nursing*.
34. Pickler, R.H., McGrath, J.M., Reyna, B.A., McCain, N., Lewis, M., Cone, S., Wetzel, P., & Best, A. (In Press). A model of neurodevelopmental risk and protection for preterm infants. *Journal of Perinatal and Neonatal Nursing*.
35. Boonmee, J., & Pickler, R.H. (In Press). Hospital-to-home transition of mothers of preterm infants. *MCN The Journal of Maternal Child Nursing*.

C. Research Support.

Ongoing Research Support

P30 NR011403 Pickler (PI) 6/1/09-5/31/14

NINR Center of Excellence in Biobehavioral Approaches to Symptom Management.

The Center will guide the development, integration, synthesis, and dissemination of current and evolving biobehavioral scientific domains, including advances in measurement and data analysis of fatigue and associated phenomena and will provide consultation to scientists in the larger biobehavioral research community.

Role: PI

2 R01 NR005182 Pickler (PI) 7/01/06-4/30/11

NINR

Feeding Readiness in Preterm Infants

The primary aim of this competing continuation is to test the model of feeding readiness developed during the non-experimental study. The study will enroll 140 infants who will be randomly assigned to one of four feeding approaches, varying maturity at feeding start and amount of feeding experience.

Role: PI

3UL1RR025747-02S3 Price (Supplement PI) 2009-2010

NCRR

Supplement to UNC Clinical and Translational Science Award (E. Pisano, PI)

Improving Outcomes Measures for Chronic Lung Disease of Prematurity
Role: Expert Panelist

R01 HS18422 Goldberg (PI) 2009-2011
Agency for Healthcare Research and Quality
An in-depth examination of performance driven primary care practices.
Role: External Auditor

Sigma Theta Tau International and American Nurses Foundation (Academy of Neonatal Nurses)
Brown (PI) 2010-2011
Mothers' attention and preterm infant feeding
Role: Co-investigator

Completed Research Support

P20 NR008988 McCain (PI) 9/15/04-9/14/09
NINR Biobehavioral Research in Critical Health Experiences
The aim of this grant is to establish an exploratory center for the study of the interaction between biology and behavior in critical health experiences.
Role: Co-Investigator, Pilot Core Director

1R01 NR005182 Pickler (PI) 2/01/01-6/30/06
NINR Bottle Feeding Readiness in Preterm Infants
The primary aim of this study was to test a predictive model of bottle feeding readiness and outcomes in preterm infants. This non-experimental, observational study used data obtained from medical records and 10 to 14 feeding observations each for 95 infants beginning at 32 weeks post-conceptual age. A model of feeding readiness was developed.
Role: PI

1R01 NR009506 Grap (PI) 1/01/07-12/31/09
NINR Sedation effects in mechanically ventilated patients.
The aim of this grant is to determine the effect of sedation in achieving sedation goals in mechanically ventilated patients across populations. A secondary aim is to identify subject and sedative factors that affect achievement of sedation goals.
Role: Co-Investigator

3R01 NR005182 Pickler (PI) 2/11/02-8/31/03
NINR Minority Supplement to Bottle Feeding Readiness in Preterm Infants
The purpose of this minority supplement is to test the relationship between bottle feeding readiness and bottle feeding outcomes in preterm infants. Supported L. Amankwaa, Minority Investigator.
Role: PI

Amankwaa (PI) 5/01/03-9/01/03
AD Williams Foundation
Assessing the Psychometric Properties of the MIRI
The purpose of this study is to further develop the Maternal Infant Responsiveness Instrument (MIRI). A proposed sample of 200 mothers with children under six months of age will complete the MIRI. Reliability of the instrument will be determined.
Role: Co-Investigator

Funded Research Consultation

R15 NR009235 McGrath (PI) 3/1/06-2/28/08
Feeding Readiness and Progression in Preterms Scale
Role: Consultant

Funded Trainees

F31 NR011268 Baker (Fellow) 1/2010-12/2012
NINR
Understanding late preterm mothers and infants.
Role: Co-sponsor

F31 NR07929 Crosson (Fellow) 9/01/02-8/31/04
NINR
The Effect of Predictable Feeding Opportunities on Preterm Infants
Role: Sponsor

Pending Applications

R01 NR012307 Pickler (PI) Pending Review
NINR/NICHD
Patterned Experience for Preterm Infants

JMU IRB Number: 11-0297

Consent to Participate in Research

Identification of Investigators & Purpose of Study

You are being asked to participate in a research study conducted by Julie A. Strunk from James Madison University. The purpose of this study is to examine the parent's experience of managing the healthcare needs of the adolescent with Autism Spectrum Disorder (ASD). This study will contribute to the researcher's completion of her doctoral dissertation.

Research Procedures

Should you decide to participate in this research study, you will be asked to sign this consent form once all your questions have been answered to your satisfaction. This study consists of an interview consisting of open ended questions that will be administered to individual participants in an office located in Blue Ridge Hall. You will be asked to provide answers to a series of questions related to your experience of managing the healthcare needs of an adolescent with an ASD. All interviews will be audiotaped.

Time Required

Participation in this study will require no more than 3 hours of your time.

Risks

The investigator does not perceive more than minimal risks from your involvement in this study. As the questions may involve sensitive topics, there may be potential for psychological risk to the subjects. Therefore, the student investigator will discontinue the interview at the request of the participants and will make available a list of psychological resources that can be accessed by the participants.

Benefits

There are no studies that have been conducted on the parent's perceptions on managing the healthcare needs of the adolescent with ASD. With the increasing numbers of children being diagnosed with ASD and with autism becoming a prominent topic in the health and educational fields, it is important to explore the lived experience of those individuals experiencing the affects of ASD. It is only from hearing their individual stories that researchers can discover how to work with and provide services for these individuals.

Confidentiality

The results of this research will be presented as a manuscript submitted to a peer-reviewed journal. The results of this project will be coded in such a way that the respondent's identity will not be attached to the final form of this study. The researcher retains the right to use and publish non-identifiable data. While individual responses are confidential, aggregate data will be presented representing averages or generalizations about the responses as a whole. All data will be stored in a secure location accessible only to the researcher. Upon completion of the study, all information that matches up individual respondents with their answers, including audiotapes will be destroyed.

Project Title: Managing the Healthcare Needs of Adolescents with Autism Spectrum Disorder: A Parent's Experience

Participation & Withdrawal

Your participation is entirely voluntary. You are free to choose not to participate. Should you choose to participate, you can withdraw at any time without consequences of any kind.

Questions about the Study

If you have questions or concerns during the time of your participation in this study, or after its completion or you would like to receive a copy of the final aggregate results of this study, please contact:

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Questions about Your Rights as a Research Subject

Dr. David Cockley
Chair, Institutional Review Board
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Giving of Consent

I have read this consent form and I understand what is being requested of me as a participant in this study. I freely consent to participate. I have been given satisfactory answers to my questions. The investigator provided me with a copy of this form. I certify that I am at least 18 years of age.

I give consent to be audiotaped during my interview. _____ (initials)

Name of Participant (Printed)

Name of Participant (Signed)

Date

Name of Researcher (Signed)

Date

Chapter Five

Managing the Healthcare Needs of Adolescents with Autism Spectrum Disorder:

The Parents' Experience

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Abstract

The purpose of this phenomenological study was to describe the experiences of parents who manage the health needs of an adolescent with Autism Spectrum Disorder (ASD). Qualitative interviews were conducted with parents from 10 families of adolescents with ASD residing in Virginia. "Parents needing help" emerged as the essence of the parents' experiences. Four themes representing the essential challenging elements of the parents' experiences included concern with medications, frustrations with healthcare services, recognizing secondary health issues, and the need for resources and services.

Keywords: Autism Spectrum Disorder, parents, healthcare needs, adolescents with autism

Parenting an adolescent with Autism Spectrum Disorder (ASD) can be a challenging and unique experience when dealing with the child's healthcare needs. Children with ASD often have multiple needs, including comorbid medical conditions, mental health issues, and developmental delays, that bring them to their primary care physician more frequently than other children (Brachlow, Ness, McPheeter, & Gurney, 2007; Gurney, McPheeter, & Davis, 2006). Parents often look to their primary healthcare provider to provide guidance in navigating specialty care such as psychopharmacological and behavioral interventions, educational and rehabilitation therapies, and complementary and alternative medicines. However, it has been reported that parents of children with ASD experience challenges when accessing healthcare for their child and dissatisfaction with treatment and guidance (Carbone, Behl, Azor, & Murphy, 2010; Harguanani, Shipman, & Reynolds, 2006). Parents also have reported a lack of advocacy for special services as well as a lack of expertise in the care of children with ASD (Brachlow et al., 2007; Carbone et al., 2010; Harguanani et al., 2006). Myers and Johnson (2007) reported that even pediatricians perceive a lack of necessary skills needed to provide the appropriate care for children with ASD. Unfortunately there apparently are discrepancies between physician and parent perceptions of the primary care needs of children with ASD (Carbone et al., 2010). Therefore, the aim of this phenomenological study was to examine the parent's experience of managing the healthcare needs of the adolescent with ASD.

Background

Parents often have the life-long challenge of negotiating health and social service systems (Ouellette-Kuntz, et al., 2005) in order to access healthcare services for individuals with ASD who often are dependent on others to understand and explain their needs (Kerr et al. 2003). The

American Academy of Pediatrics has advocated for a medical home model of primary pediatric care (Brachlow et al., 2007). This model is defined as healthcare that is accessible, continuous, comprehensive, family-centered, compassionate, culturally effective, and coordinated with specialized services (American Academy of Pediatrics, 2002). According to studies by Palfrey and colleagues (2004) and Limb and colleagues (2001), parents of children with special healthcare needs who received care consistent with this model reported greater healthcare satisfaction and better overall health for their children in comparison to parents of similar children without such care. Filipek et al. (2000) reported that 30% of parents of children with ASD were offered no help with education, therapy, or parental support groups, and that only 10% of the parents thought that their child's problems were clearly explained to them by their healthcare provider. A study by Krauss et al. (2003) reported that parents of children with ASD were twice as likely to report difficulty in accessing subspecialty care as compared to parents of children with other special healthcare needs.

An adolescent's autism diagnosis affects every member of the family in numerous ways (Beresford, 1994; Prilleltensky & Nelson, 2000; Strunk, 2010). Parents and/or caregivers often place their primary focus on helping their adolescent with ASD, which may put strains on their marriages, other children, work, finances, and personal relationships and responsibilities (Raina, et al., 2004; Strunk, 2010). Parents have to shift much of their time and financial resources toward providing treatment and interventions for their adolescents, perhaps to the exclusion of other priorities (Raina et al., 2004).

Compounding the problem, adolescents with ASD may often have comorbid diagnoses or health issues such as tuberous sclerosis complex, fragile X syndrome, Down syndrome, and Prader-Willi syndrome (Zafeiriou, Ververi, Vargiami, 2007). These individuals usually display

problems related to neurological issues as well as nutritional, gastrointestinal and orthopedic problems (Souders, DePaul, Freeman, & Levy, 2002; Strunk, 2009). Due to the lack of specific pathophysiology, adolescents with ASD are often treated based on their symptomology and many are on a plethora of medications (Cole, 2008; Strunk, 2009).

Adolescents with autism also have the same basic healthcare needs as adolescents who are without disabilities (Cole, 2008; Strunk, 2009). Many are susceptible to risky health behaviors such as experimentation with smoking, alcohol, and drug use (Klein & Wilson, 2002). Just like neurotypical adolescents, they also experience high levels of stress, decreased physical activity, unsafe sexual activity, depression, and suicide (Klein & Wilson, 2002). Because of this as well as past findings that indicate their healthcare needs are not being sufficiently met, further research is needed to understand the complex healthcare needs of adolescents with autism.

Method

Research Design

We used phenomenological methods to ascertain parents' perspectives of managing the healthcare needs of adolescents with ASD. The purpose of phenomenological research is to illuminate and identify phenomena through the perception of individuals who experience the phenomena (Creswell, 2007); in this case, a parent's experience in managing the healthcare needs of the adolescent with ASD. This is accomplished through inductive, qualitative methods such as interviews, discussions and participant observation, and representing the phenomenon from the perspective of the research participant(s) (Creswell, 2007). Phenomenology is concerned with the study of experience from the perspective of the individual, with the researcher bracketing his or her own assumptions and usual ways of perceiving (Creswell, 2007). Ontologically, human experience is considered to be preeminent and fundamental, and reality is

measured as the whole experience that is detailed in thinking, feeling, and willing (Mitchell & Cody, 1999). Epistemologically, phenomenological approaches are based on a paradigm of personal knowledge and subjectivity and emphasize the importance of the personal perspective and interpretation (Creswell, 2007). This personal perspective and interpretation are of importance for understanding the individual's experience such as that of the parent of an adolescent with ASD. Personal perspective and interpretation also provides insights into people's motivations and actions (Creswell, 2007), as in this study by exploring parents' perceptions of how they manage their adolescents' healthcare needs. Finally, personal perspective and interpretation allow for the dismantling of assumptions (Creswell, 2007), in this study by taking into account the healthcare needs of the adolescent with ASD.

Phenomenological research in nursing is one of several methods that can be used to explore the experiences of others. Writing through the lens of phenomenology allows the researcher to focus on describing what groups of participants have in common as they experience a particular phenomenon (Creswell, 2007). Various approaches within phenomenology can be used to guide the research. Because there is more than one legitimate way to proceed with a phenomenological investigation, the researcher can choose an approach that offers the most rigorous and accurate interpretation of the phenomenon under investigation and that is most congruent with his or her own philosophic beliefs.

Participants

Creswell (1998) and Sandelowski (1995) recommended that the phenomenologist interview a small number of individuals, generally no more than 10. With this in mind, 12 parents (mother, father, or both) of adolescents between the ages of 10 to 18 with ASD were interviewed for this study. Moustakas (1994) recommended that participants be selected

according to two criteria: (a) they are experiencing the phenomenon being studied, and (b) they are willing to participate in the study and willing to be interviewed. Parents were purposefully chosen to participate in this study because of their experience in managing the healthcare needs of their adolescent with ASD and their willingness to share their experience. Parents were excluded if they were not the primary caregiver of the adolescent or if the adolescent with ASD was adopted.

Data Collection

The study was approved by an institutional review board and all participants gave informed written consent. The participants were recruited through newspaper advertisements, flyers, and by word of mouth. The advertisement included a description of the study, the purpose, and the procedure. Each interview took place in a quiet conference room at an area university. Before each interview, each participant was given an informed consent form explaining the nature of the study as well as information regarding how data would be shared and how confidentially would be maintained. Participants also were informed that any recordings, notes, or other interview material would be stored in a locked cabinet in the primary investigator's office. All interviews were audiotaped and the length of each interview varied from 1 to 3 hours. The first author conducted all interviews and transcribed the audiotapes. The interview was an interactive process between the participants and the researcher using open-ended questions with follow-up questions used to assist in clarifying and understanding the information presented. Guiding questions included: (1) Tell me what it's like to be the parent of an adolescent who has autism, (2) How have you changed as a parent since your child entered adolescence? (3) Tell me about your adolescent's healthcare needs, (4) How do you manage your adolescent's healthcare needs? (5) Do you have help in managing your adolescent's healthcare

needs? Parents were also asked where they perceived their adolescent to be on the spectrum according to their level of function (Table 1). Parents were allowed to choose their own words without any prompting from the researcher.

Data Analysis

Data were analyzed using Moustakas' (1994) method of analysis of phenomenological data and depicted in Figure 1. Epoché was the first step of the phenomenological reduction process. "Epoché refers to the period of examination when a researcher identifies bias and removes all traces of personal involvement in the phenomena being studied to achieve clarity of perception" (Marshall & Rossman, 1995, p. 82). This approach was taken at the beginning of the study so that the researcher could set aside her views of the phenomenon and focus on the views reported by the parents (Moustakas, 1994). By clearing her mind through the epoché process, she recalled her own personal and professional experiences in working with children with ASD. Bracketing occurred along with the epoché throughout the study as well. Bracketing is suspending or setting aside biases and everyday understandings, theories, beliefs, assumptions, and judgments (Daniels, 2005). Through the bracketing process, the researcher continuously reflected and meditated on personal experiences, letting any preconceptions and prejudgments enter and leave her mind. The second stage in the phenomenological process was the horizontalization phase. This involved reading through the transcripts of interviews and field notes and then listing significant statements (Kakulu, Byrne, & Viitanen, 2009). The third stage involved development of invariant qualities and themes. At this stage, the researcher set aside those statements that were deemed irrelevant to the topic as well as those which were repeated or overlapping. The researcher examined the identified significant statements and clustered them into themes or meaning units (Kakulu et al., 2009). The fourth stage, known as imaginative

variation, was done to facilitate the development of *textual* descriptions for each participant that described the “what” of the experience and *structural* descriptions for each participant that described “how” it was experienced (Kakulu et al., 2009). This was accomplished by retelling the story as heard by the researcher using descriptive words for the “what” of the experience and then elaborating on these words to describe “how” the experience was perceived. The last stage of the process was the synthesis of meaning in which the researcher integrated the textures and structures from each participant’s experience in order to construct the essence of the phenomenon (Kakulu et al., 2009). The essence is the shared meaning of the experience of participating parents as they manage the healthcare needs of their adolescents with ASD.

Trustworthiness

This study maximized credibility by using three strategies: prolonged engagement, peer debriefing, and member checking. Prolonged engagement requires that the researcher becomes immersed in the work, which in this study included bracketing, lengthy interviews, and reiterative data processes that involved direct interview transcription by the researcher, and extensive time reading, thinking about, and analyzing the data. Peer debriefing requires that the researcher select one or more qualified peers who will discuss interpretations and concerns. The researcher connected via email and telephone with one of her colleagues in order to critically review the implementation and evolution of the research methods. The role of the peer debriefer was to facilitate the researcher's consideration of methodological activities and provide feedback concerning the accuracy and completeness of the researcher's data collection and data analysis procedures. Member checking requires that the researcher obtain feedback from the research participants (Lincoln & Guba, 1985). This feedback is particularly useful when the analysis and interpretation have been made and conclusions have been drawn (Tutty, Rothery, & Grinnell,

1996; Guba, 1981). Participants were sent a copy of the textural/structural descriptions created from their own interview data along with a red marker and a letter explaining the need for review and revision of any statements made. Very few changes or queries were raised; these were noted in the final, composite description.

In qualitative research, responsibility for transferability falls to both the researcher and the person seeking to apply the information (Lincoln & Guba, 1985). Transferability is enhanced by maintaining an inquiry audit (Lincoln & Guba, 1985) consisting of notes related to the data-collection and data analysis processes, original transcripts with researcher reactions and thoughts, and consultation with an experienced and qualified expert to review or audit the consistency of the research process. This was accomplished by the participation of an expert in qualitative research who performed an extensive inquiry audit throughout the research process.

Findings

Twelve parents participated in the study over a data collection period of four months. Table 1 outlines demographic characteristics of the children of the participants. The essence of the phenomenon was *parents needing help in order to meet the healthcare needs of their adolescents with ASD*. The experience of caring for the healthcare needs of an adolescent child with autism was described by parents as quite challenging. Parents also reported the experience to be difficult, stressful, and time consuming. This essence is revealed in the four themes that were distilled during the integration of the individual participants' structural and textural statements: concern with medications, frustrations with healthcare services, recognizing secondary health issues, and the need for resources and services.

Parent's Need for Help: Concerns about Medications

When talking about managing the adolescent's healthcare needs, parents spoke about their concern with medications. Parents often stated that they were worried about the type and amount of medication their adolescent was prescribed. One parent stated, "It's very frustrating for me because he's on an enormous amount of medication." There were concerns regarding the various side effects that might be experienced. One parent stated, "I want to know the side effects. I want to know if this is this going to make him sterile, or if it will affect his liver or his heart." Another parent stated, "I read those medical warnings about suicidal risk and all that kind of stuff and it just sets me in a panic." There were also concerns about the difficulty in getting their adolescent to take medications. Parents of older adolescents expressed that it was difficult getting their adolescent to be compliant in taking their medication because the adolescent didn't want to be different from his or her peers. One parent stated, "He just wants to be like the other kids so he quit taking his meds." Another parent stated, "I'm kind of conflicted because I don't want to overmedicate my child, however, if the medication is going to help him and if it's something that's going to be very beneficial to him, then I'm all for it." Some parents stated that medication compliance was difficult because their adolescent seemed afraid to take prescribed medication, while others stated that they had to be very exact in their wording in order for the adolescent to understand their directions in taking medication. Finally, there was concern expressed about the role that pharmaceutical companies played in the prescribing of medications to their adolescents with ASD: In particular, there was anxiety related to whether or not their children were being treated as "guinea pigs." Another parent stated, "I don't know what [role] the drug companies play in all of this but I'm sure that there's more pressure for people to try drugs that maybe they shouldn't be trying."

Parent's Need for Help: Frustration with Healthcare Services

Parents voiced their frustrations related to healthcare services. They stated that they had little faith in the healthcare community due to lack of general knowledge about ASD. One mother stated, “I felt like I had to educate the doctors regarding my son’s autism.” Parents were also frustrated with the inadequate care and attention that their adolescent received from primary care providers. One parent stated, “It was very frustrating for me to have a doctor who sees her but doesn’t really know her, to look at her chart and state that she’s all drama and not take the moment as being legitimate for what it is.” Another parent stated, “I just got frustrated with the whole medical community, kind of feeling like they were blowing me off and were not just helping me so I kind of stopped going down that road.” Another said, “I really wish we had a pediatrician that worked hand-in-hand with us for all these kinds of things, seeing her as a whole person and not just someone with ASD.” Many parents voiced concerns about how they were perceived negatively as parents and how their adolescents were negatively treated. As stated by one parent, “Some doctors acted like we were just totally stupid and would not listen [to us].” One mother was frustrated because the physician was visibly uncomfortable working with her son. She stated, “I’ve taken my son to a doctor who really didn’t know how to deal with him, so we couldn’t go back.” Finally, parents spoke about the challenges in dealing with specific medical procedures such as the adolescent receiving an injection, having blood drawn, or dental care. They spoke of the importance of preparing the adolescent before any medical procedure. Some procedures such as dental care required that the adolescent be anesthetized. One mother stated, “It’s very difficult to take him to the doctor’s office because he is so hard to manage. He will have a meltdown.” Others reported difficulties during dental and healthcare visits. Another parent stated, “The dentist has to completely put him to sleep. He won’t even get in the chair

awake.” Yet another parent stated, “It often takes several people to hold him down if he needs an injection.”

Parent’s Need for Help: Recognizing Secondary Health Issues

All parents voiced concerns about the number of secondary health issues their adolescent experienced. These health issues involved seizures, constipation and diarrhea, celiac disease, and lactose intolerance. One mother stated, “She’s not only autistic, she’s epileptic and it is time consuming with that, and so with taking care of all her medical needs I had to quit work.”

Parents also addressed problems with personal hygiene, sleep, and safety. One parent stated, “Sleep is probably the biggest stressor.” They spoke of having to assist their adolescent in personal hygiene practices. They also spoke of having to give step-by-step instructions when explaining the process of bathing and brushing teeth. As one father stated, “I have to really stay on him about brushing his teeth and taking a shower. We have to make sure that he’s using soap on his whole body.” Sleep disturbances also created problems for the parents because the adolescent would get up during the night and wander around the house, making sleep difficult for the parent and siblings. One mother stated, “He’ll just wander around the yard at night and you’ll just see him looking in our window.” Safety was also voiced as a concern because the adolescent lacked the ability to understand the concepts of harm and danger. Some parents of older adolescents voiced concerns about dealing with their child’s hormonal changes and the effects this had on the adolescent’s behavior. Several spoke of their uneasiness with issues surrounding menstruation. Others spoke about concerns dealing with masturbation and unsafe sexual behavior as well as other risky behaviors. One parent of a younger, low functioning child stated, “He’s a huge safety risk; he doesn’t understand safety or the concepts of safety. He doesn’t understand that if he stands in the road flapping his hands he could get hit by a car and

die.” Yet the parent of an 18-year old high functioning child stated, “Somebody dared my son to snort a whole pill of OxyContin and he did and it almost killed him.” Several parents talked about their adolescents’ inabilities to make good choices in dressing modestly and their inabilities to recognize problems such as unwanted attention, sexual harassment, and possible rape that could ensue once secondary sexual characteristics started to develop.

Parent’s Need for Help: Need for Specific Resources

Parents voiced a concern about the lack of services in general for adolescents with ASD and repeatedly spoke about the need for specific resources and assistance in dealing with their adolescents’ healthcare issues. Many parents stated, “I wish there were more services and that they [doctors] knew what to do.” One parent stated, “I don’t feel that there’s been enough [research] in different areas in adolescents or in the younger ages to know how to adequately treat these children.” They talked about the specific need for educating not only themselves but others as well. One parent stated, “I feel like I’m a fighter and I have to investigate it myself.” There was a general consensus among parents that services were needed in order for their adolescents to function successfully at home, at school, and in the community. Many parents stated, “We cannot do it without services or resources out in the community.” Parents felt as if they did not get support and referrals from the healthcare community and they felt as though they were totally responsible for finding their own services and resources. As stated by one mother and father, “You have to beg and ask for medical services. It’s not just somebody advertising that they’re doing this for autism.”

Discussion

The aim of this study was to gain a better understanding of the lived experience of parents who manage the healthcare needs of their adolescent with ASD. Parents talked about not

only aspects of their parenting role but also other aspects of their lives that were essential to their experience of managing their adolescent's healthcare needs. Statements represented both high-functioning and severely affected adolescents, with level of functioning being based totally on the parent's perception. The essence of their experience can be summed up as their needing help in managing their adolescent's healthcare needs. This essence was revealed in the four themes that were found in the integration of each participant parent's interpreted experience: concerns about medications, frustration with healthcare services, recognizing secondary health issues, and need for specific resources.

The parents in this study expressed a concern with medicating their adolescents. They were frustrated with the number and types of medications being prescribed for their adolescent and voiced concern that their adolescents were given medications that had not been adequately tested for children. According to Bellando and Lopez (2009), adolescents with ASD are prescribed numerous medications to improve functioning and help with behavioral and emotional management at home and at school. Several parents were concerned with the role of pharmaceutical companies and their child's prescribed medication. Parents were also concerned with the side effects and long-term outcomes when taking certain medications. Previous researchers (Posey & McDougle, 2001) found that risperidone was often used to reduce aggression, hyperactivity, impulsivity, oppositionality, repetitive behavior, and self-injury. However, they found no published placebo-controlled studies of risperidone in children and adolescents with autism.

Parents in the study also voiced concerns about their adolescent's noncompliance in taking their medication, stating that the adolescent felt different when on the medication and this difference affected their interaction with peers. Swiezy and Summers (1996) found that parents

were often responsible for administration of medication and the extent of noncompliance with prescribed dosages was potentially affected by the parent's perception of the efficacy of the treatment. They additionally found that the parent was the most knowledgeable regarding their child's behavior and had unique control and influence regarding medication administration.

Parents in the study additionally expressed frustration about their adolescent's healthcare providers' actual knowledge about ASD; the parents perceived a lack of support and guidance from these providers. Woodgate, Ateah, and Secco (2008) found that parents thought healthcare providers needed to be more receptive to both dealing with their adolescent's secondary health issues and their need for consistency in healthcare provision. Parents spoke about dealing with secondary healthcare issues that often caused behavioral problems for the child. Kogan, Strickland, Blumber, Singh, Perrin, and van Dyck (2008) found that children with ASD had higher rates of comorbidities, including epilepsy, gastrointestinal problems, anxiety and depression, and respiratory, food, and skin allergies which may contribute to behavior problems. Additionally, families of children with ASD have more financial problems, provide significant amounts of healthcare coordination (more than 10 hours a week) for their own children, and are more likely to stop or reduce work than families of other groups of children with special needs (Lord & Bishop, 2010; Honberg, Kogan, Allen, Strickland, & Newacheck, 2009; Kogan, et al., 2008).

Maintaining good hygiene was another concern parents had with their adolescent as well as maintaining good sleep habits. Matson and colleagues (2009) found that individuals with autism who were highly impaired had difficulties when it came to adaptive functioning that was associated with personal hygiene and grooming behaviors. Hoffman and colleagues (2008) found that sleep problems of children with autism and other developmental disabilities adversely

affected their families and contributed to parents' stress. Through a variety of measurement procedures, including sleep electroencephalography (EEG) or polysomnography (PSG), actigraphy, sleep diary, and sleep questionnaire studies, Richdale and Schreck (2009), consistent with the findings of other researchers, found that individuals with ASD experienced more sleep problems than the general population.

Across levels of parent-reported levels of functioning, parents reported that safety issues were a real concern for them because their adolescents seemed to have little safety awareness. Children with autism have been noted to be at significant risk for increased accidental injury and death (Finlayson, Morrison, Jackson, Mantry, & Cooper, 2010). Some children with ASD have particular risk factors, including a pervasive interest in water, poor danger awareness, ingestion of nonfood items including hazardous substances, and a propensity to run from home or from family members (Summers, Tarbox, Findel-Pyles, Wilke, Bergstrom, & Williams, 2011; Abbeduto, Seltzer, Shattuck, Krauss, Orsmond, & Murphy, 2004). Many children with ASD require intense supervision and are adept at escaping, even from carefully secured homes. Auto safety is an additional challenge for children with behavioral issues who will not remain seated in a regular lap belt (Huang, Kallan, O'Neil, Bull, Blum, & Durbin, 2009).

Parents in this study also voiced concerns about their adolescent's hormonal changes as well as behavioral changes that occurred during adolescence. Burke, Kalpakjizn, Smith, and Quint (2010), in a study of adolescent girls with autism, Down syndrome, and cerebral palsy who were evaluated retrospectively regarding gynecological complaints, found that girls with autism were significantly more likely to present with behavioral problems.

Parents in the study also spoke about their fears concerning their adolescent taking part in risky behaviors as well as sexual relationships and masturbation. Hellemans and colleagues

(2007) also found that adolescents with ASD expressed concerns and frustrations in connection with risky behaviors including those concerned with sexuality and relationships with other individuals. Carpenter (2009) found that individuals with ASD often learned that various substances were fun and that the use of alcohol as well as cannabis could introduce the user to an accepting and tolerant social group.

Challenges encountered in healthcare settings were an additional area of parental concern. Parents stated that it was often difficult to prepare their adolescent for medical procedures and many of the adolescents displayed negative, disruptive, and potentially dangerous behaviors when confronted with blood draws, physical exams, or dental procedures. Birkan, Krantz, and McClannahan (2010) noted that parents reported their children with ASD struggling or attempting to flee when immunizations or other injections were attempted. Tantrums and attempts to escape sometimes lead to physical restraint, making it more difficult for them to receive treatment (Birken et al., 2010). Some children with ASD require general anesthesia for relatively benign procedures such as dental examinations (Luscre & Center, 1996). Of concern is that some physicians and dentists, after repeated experiences with children who struggled and engaged in aggressive and disruptive behavior, refused to retain them as patients, leading to increased difficulty for parents in finding adequate healthcare for their adolescents.

Parents in this study perceived that there really were no resources specifically for adolescents with autism between the ages of 13 and 18. In fact, Mulligan and colleagues (2010) noted that there is a lack of consensus about how best to support families after a child of any age has been diagnosed with ASD. And unfortunately, parents frequently report dissatisfaction with the quality of information given and the manner in which the diagnosis of autism was delivered by health care providers (Mulligan, Steele, MacCullough, & Nicholas, 2010; Howlin & Moore,

1997). In this study, a parent reported having “to beg and ask for medical services.” Parents have reported in other studies that they have had to locate information on their own, which increased their feelings of worry and hopelessness because of the questionable credibility and negative tone of information found (Mulligan et al., 2010; Osborne & Reed, 2008). Parents’ informational needs have been found to change as their children age, with parents of older children desiring information targeted to key junctures in their child’s life such as the onset of puberty (Mulligan et al., 2010; Osborne, 2008). Many parents in the current study were in agreement that “none of the information or literature covered adolescents with ASD.”

Findings of the current study revealed key factors to be considered in the development and delivery of help in managing the ASD adolescent’s healthcare needs. First, these findings suggest that more studies are needed about the medications currently prescribed for adolescents with ASD and particularly about medication effectiveness. Moreover, adolescents with autism need a thorough health examination before any medications are prescribed in order to establish the severity and pattern of the adolescent’s behavioral problems. Careful assessment would also consider what previous treatments have been tried and those currently in place. Finally, in children with severe behavioral problems, it may not be a matter of selecting medication or behavioral therapy but rather to combine these approaches (Frazier, Youngstrom, Haycock, Sinoff, Dimitriou, Knapp, & Sinclair, 2010). Healthcare providers should offer needed information related to medications and behavioral therapies to parents. They should also advocate on the patient’s behalf when there is concern or worry about over medication or medication side effects and provide instruction on proper administration techniques that can be used for adolescents with autism. This could be accomplished through the use of social stories or pictorial aides. There is a need for the development of guidelines for caring for adolescents with

ASD that could be used by primary healthcare providers. These could be incorporated into the use of the Medical Home Model referred to in studies by Brachlow et al. (2007) and Carbone et al. (2010).

Parents in this study had some negative perceptions towards healthcare providers. While it is unknown how widespread these perceptions are, it is likely that changes are needed in the healthcare system in order to improve effectiveness in care delivery for adolescents with ASD. A unique opportunity exists for parents and healthcare providers to partner in the development and implementation of systems of care that would benefit adolescents with ASD and their parents. This might include increased time and follow up with the assessment team to further discuss diagnosis and resources. For this to happen, healthcare providers need to increase their understanding of ASD and of the areas of advocacy and participatory guidance that would be most beneficial for adolescents with ASD and their parents.

Information for parents of adolescents with ASD is also needed. Written resources, including print copies and websites that include region-specific information as well as local support services are needed. This could be achieved by a general and broadly-applicable section or module within a resource book or books that are common across regions, with additional modules that contain local resources. Reflection of cultural diversity and the range of experiences across the ASD spectrum are needed in these resources. Diverse examples and scenarios with relevance to the target community would add to the value of these resources. Nurses can play a vital role in creating these resources and modules and providing health education that is geared towards the adolescent with ASD. Nurses can also provide direction concerning resources and support services in their communities and across the region.

Conclusion

This qualitative study represents original findings related to the experience of parents managing the healthcare needs of an adolescent with ASD. The results of the study confirmed that managing the adolescent's healthcare needs was frustrating and challenging and that parents had a need for help in managing these needs. Nurses can be integral in helping parents to overcome frustrations and challenges by becoming more aware of the ASD spectrum of neurobiological disorders, by creating and planning interventions for parents, by sharing information regarding resources and services, and by collaborating with others in the healthcare field to provide services for adolescents and their families. Additional research, both qualitative and quantitative, is needed to understand how both parents and adolescents with ASD experience this developmental period. Further research may also help to identify specific as well as more universal needs of adolescents and families, along with the usefulness of existing resources and treatments. As resources increase, including pharmaceutical and non-pharmaceutical treatments, efficacy trials will be necessary. Given the increasing precision of screening and thus the increasing rate of ASD diagnoses (Hertz-Picciotto & Delwiche, 2010; King & Bearman, 2009; Waterhouse, 2008), it is important that these research efforts be given priority.

Chapter Six

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Appendices

Appendix 1

A Summary of the levels of Evidence and Articles Reviewed

Level of Evidence	Definition	Number of articles reviewed
I	Evidence from a systematic review or meta-analysis of all relevant randomized controlled trials (RCTs), or evidence-based clinical practice guidelines based on systematic reviews of RCTs	0
II	Evidence based from at least one well-designed RCT	0
III	Evidence obtained from well-designed controlled trials without randomization	0
IV	Evidence from well-designed case-control and cohort studies	18
V	Evidence from systematic reviews of descriptive and qualitative studies	0
VI	Evidence from systematic reviews of descriptive and qualitative studies	7
VII	Evidence from the opinion of authorities and/or reports of expert committees	0

Note: Definitions from Melnyk and Fineout-Overholt (2005)

Appendix 2

Table 2 Cooper's Five Stages of Research Synthesis

Problem formulation
Data collection
Data evaluation
Analysis and Interpretation
Presentation of results

Cooper (1998)

Appendix 3

A Summary of the levels of Evidence and Articles Reviewed

Level of Evidence	Definition	Number of articles reviewed
I	Evidence from a systematic review or meta-analysis of all relevant randomized controlled trials (RCTs), or evidence-based clinical practice guidelines based on systematic reviews of RCTs	0
II	Evidence based from at least one well-designed RCT	0
III	Evidence obtained from well-designed controlled trials without randomization	0
IV	Evidence from well-designed case-control and cohort studies	18
V	Evidence from systematic reviews of descriptive and qualitative studies	0
VI	Evidence from systematic reviews of descriptive and qualitative studies	7
VII	Evidence from the opinion of authorities and/or reports of expert committees	0

Note: Definitions from Melnyk and Fineout-Overholt (2005)

Appendix 4

Summary of Studies Investigating the Affects of Having a Child with Autism Spectrum Disorder

Author	Sample	Variables	Hypothesis/Research Question	Results
<p>Altieri et al (2009), <i>Journal of Child and Family Studies</i></p> <p>United States</p> <p>Level of Evidence: IV</p> <p>Emerging Theme: Social Support</p>	<p>N=52 (26 mothers /26 fathers)</p> <p>Age range of children: 3-16 years</p>	Coping, social support	<p>(1) Mothers would have higher ratings of the family's coping mechanisms than fathers</p> <p>(2) Mothers would be more likely to rate their family as cohesive and adaptable and be more satisfied with the functioning of the family than fathers</p> <p>(3) Mothers would perceive more social support than fathers</p> <p>(4) Moderate levels of family cohesion and adaptability would significantly relate to higher levels of perceived social support and implementation of other positive coping behaviors</p>	<p>(1) Mothers who rated their family as enmeshed or connected were significantly more likely to use coping mechanisms than fathers who rated their family as disengaged.</p> <p>(2) There was not a significant difference between participants' ratings of the actual and ideal functioning of the family, which indicated that these parents were generally satisfied with family functioning.</p> <p>(3) Mothers were more likely than fathers to perceive high levels of social support from friends and from family.</p> <p>(4) The two samples of mothers and fathers were found to be significantly different suggesting that families with a child with autism have a different distribution of types of adaptability when compared to families without children with autism</p>
<p>Benson, P.R. (2006), <i>Journal of Autism and</i></p>	<p>N= 60 mothers and 8 fathers.</p>	Severity of symptoms, stress proliferation, social support	(1) Child symptom severity and stress proliferation would both be	(1) Child symptom severity was significantly and positively correlated

<p><i>Developmental Disorders</i></p> <p>United States</p> <p>Level of Evidence: IV</p> <p>Emerging Theme: Stress</p>	<p>Age range of children: 3-7 years</p>		<p>significantly associated with parent depression</p> <p>(2) Stress proliferation would account for a significant increase in the explained variance in parent depression beyond that attributable to child symptom severity alone</p> <p>(3) The effect of child symptom severity on parent depression would be at least in part indirect, due to the mediating role of stress proliferation</p> <p>(4) The negative effect of social support on stress proliferation would be greatest when child symptom severity was less, rather than more, severe</p> <p>(5) The negative effect of social support on parent depression would also be greatest when child symptom severity was less severe.</p>	<p>to both stress proliferation and to parent depression</p> <p>(2) Child symptom severity was found to be significantly and positively associated with stress proliferation; however, informal parent support was significantly and negatively related to both stress proliferation and to parent depression</p> <p>(3) Child symptom severity was found to be a highly significant and positive predictor of parent depression</p> <p>(4) The interaction between child symptom severity and informal support did make a significant independent contribution to the prediction of stress proliferation. This significant interaction indicated that the effect of informal parental support on stress proliferation varied significantly depending on the level of child symptom severity</p> <p>(5) Informal social support did not significantly affect parental depression, therefore hypothesis 5 was rejected</p>
<p>Benson & Karlof (2009), <i>Journal of Autism and Developmental Disorders</i></p> <p>United States</p> <p>Level of Evidence: IV</p> <p>Emerging Theme: Stress</p>	<p>N=90 mothers and fathers (84 mothers and 6 fathers)</p> <p>Age range of children: mean age of 7.6 years</p>	<p>Stress proliferation, autism spectrum disorder, depression, anger, social support</p>	<p>(1) Would changes in stress proliferation be positively related to changes in parent depressed mood?</p> <p>(2) Would the impact of child symptom severity on parent depression be mediated by stress proliferation?</p> <p>(3) Would the impact of stress</p>	<p>(1) Stress proliferation was found to be a significant predictor of change in parent depressed mood</p> <p>(2 and 3) Stress proliferation was found to mediate the relationship between child symptom severity and parent depressed mood, with increases in child symptom severity leading to increase in stress proliferation which,</p>

			<p>proliferation on parent depressed mood be mediated by anger?</p> <p>(4) Would the impact of child symptom severity on stress proliferation be mediated by parent anger?</p> <p>(5) Would an increase in parent social support over time be associated with decreases in both stress proliferation and parent depressed mood?</p>	<p>in turn, resulted to increases in parent depressed mood.</p> <p>(4) It was found that anger could affect parent well-being in both direct and indirect ways. Parent anger was found to exert a powerful direct effect on both stress proliferation and parent depression. Parent anger was also found to partially mediate the effect of child symptom severity on stress proliferation. It was also found that anger mediated the effect of stress proliferation on depressed mood, with increased stress proliferation leading over time to increased parent anger which, in turn, led to increased parent depression. Therefore, anger served both as an important cause and an important effect of stress proliferation among parents of children with ASD.</p> <p>(5) Informal social support was found to exert a significant negative ‘‘main effect’’ on parent depressed mood. Informal support was found not to be a significant predictor of stress proliferation. However, child symptom severity did not moderate the effect of informal support on stress proliferation.</p>
<p>Bilgin & Kucuk (2010), <i>Journal of Child and Adolescent Psychiatric Nursing</i></p> <p>Turkey</p> <p>Level of Evidence: VI</p> <p>Emerging Theme: Stress</p>	<p>N=43 mothers</p> <p>Age range of children: 6-17 years</p>	<p>Family roles, stressors, coping strategies, experience, expectations, support resources</p>	<p>Purpose of this study was to explore and categorize the experiences of mothers with an autistic child, with a qualitative phenomenological approach.</p>	<p>Categories/Themes consisted of the following:</p> <ul style="list-style-type: none"> • Burden of role • Role sharing • Factors related to illness • Financial problems • Healthy ways of coping with stress • Unhealthy ways of coping

				<p>stress</p> <ul style="list-style-type: none"> • Individual/emotional experiences • Collective/social experiences • Future is about children with autism • Monetary support resources • Emotional support resources • No support resources • For everyday activities • Formal education • About illness
<p>Brobst et al (2009), <i>Focus on Autism and Other Developmental Disabilities</i></p> <p>United States</p> <p>Level of Evidence: IV</p> <p>Emerging Theme: Social Support</p>	<p>N=25 couples whose children have ASD (including diagnoses of autism, Asperger syndrome, or pervasive developmental disorder not otherwise specified) and N= 20 couples whose children do not have developmental disorders.</p> <p>Age range of children: 1 month to 12 years</p>	<p>Stress, relationship satisfaction, social support, spousal support, respect</p>	<p>(1) Parents of children with ASD will report greater stress than will parents of children who do not have developmental disorders</p> <p>(2) Parents of children with ASD will report less relationship satisfaction, social support, spousal support, respect for their partners, and commitment than will parents of children who do not have developmental disorders</p> <p>(3) Parents of children with ASD who have lower perceived social support will report lower relationship satisfaction than either parents of children with ASD who have higher perceived social support or parents of children who do not have developmental disorders</p> <p>(4) Parental stress will be positively related to the child's level of special need (perceived intensity of the child's behavior problems and number of behavior problems) and to the perceived severity of the child's</p>	<p>(1) ASD reported more parental stress, and a greater number and higher intensity level of behavior problems, than couples whose children do not have developmental disorders</p> <p>(2) Couples whose children have ASD also reported less relationship satisfaction and less social support than couples whose children do not have developmental disorders. Fathers reported significantly less social support than mothers</p> <p>(3) Parents of children with ASD reported less relationship satisfaction than comparison parents, and that parents with high levels of social support reported greater relationship satisfaction than parents with low levels of social support</p> <p>(4) Parental stress was positively related to the intensity of the children's behavioral problems and to the perceived severity of the children's disabilities. Parental stress was not significantly related to the number of</p>

			<p>disability</p> <p>(5) Parental stress will be negatively related to relationship satisfaction, social support, respect for their partners, and commitment</p> <p>(6) The set of variables that predicts relationship satisfaction will differ for parents of children with ASD and parents whose children do not have developmental disorders.</p>	<p>the children's behavior problems</p> <p>(5) For mothers of children with ASD, parental stress was negatively related to relationship satisfaction and commitment. For fathers of children with ASD, parental stress was negatively related only to total social support.</p> <p>(6) For mothers whose children do not have developmental disorders, parenting stress was negatively related only to total social support. For fathers whose children do not have developmental disorders, parental stress was negatively related to relationship satisfaction, total social support, spousal support, respect for partner, and commitment. For mothers of children with ASD, the intensity of behavior problems in their children was significantly, negatively correlated with spousal support and with respect for their partners. For fathers of children who do not have developmental disabilities, the total amount of social support they received was significantly correlated with their respect for their partners, whereas those variables were unrelated for fathers of children with ASD.</p>
<p>Cashin et al (2004), <i>International Forum of Psychoanalysis</i></p> <p>Australia</p> <p>Level of Evidence: VI</p>	<p>N=9 Parents</p> <p>Age range of children: 4-10 years</p>	<p>Autism, parenting</p>	<p>A phenomenological study was undertaken to explore the lived experience of parenting a child with autism.</p>	<p>Negatives:</p> <p>(1) Less spontaneity in action and communication</p> <p>(2) Less social contact</p> <p>(3) Less things</p>

Emerging Theme: Social Support				(4) Less self Positives: (5) The Triumph of Connection (6) Patience
Dale et al (2006), <i>Autism</i> Scotland Level of Evidence: VI	N=7 mothers and 2 fathers. Age range of children: 3-11 years	Locus of cause, stability, controllability	(1) Locus of cause: mothers who see themselves to blame for their child's disorder will feel less competent as mothers (2) Stability: mothers who see their child's disorder as stable or unchanging will have lower expectations for their child in the future (3) Controllability: mothers who feel they have no personal control over their child's disorder will have higher symptoms of depressed affect and helplessness	(1) Locus of cause – All mothers had speculated about the cause of their child's disorder. A wide range of possible causes was mentioned including birth, pregnancy, MMR, genetics, biological and maternal behaviors (2) Stability - Mothers had interpreted the diagnosis in different ways, indicated by the variety of views regarding stability. There was a clear theme of uncertainty regarding the prognosis of course of ASD (3) Controllability – mothers also expressed various beliefs about who had control over helping their children
Davis et al (2008), <i>Journal of Autism Developmental Disorders</i> United States Level of Evidence: IV Emerging Theme: Stress	N=54 families Age range of children: Average age of 26.9 months	Parental stress, autism symptoms, children's problems, competence behaviors, children's cognitive level	(1) To investigate the nature of mothers' and fathers' experience of stress among parents who are newly adjusting to their toddler's diagnosis of ASD (2) To determine whether mothers and fathers report similar or different levels of parenting stress (3) To examine the relation of autism symptoms, children's problems and competence behaviors, and children's cognitive level to maternal and paternal parenting stress.	(1) The most stressful area of parenting for mothers and fathers related to the parent-child relationship and the difficult behaviors that were exhibited as well as parental perceptions that the child did not like them due to the child's dislike of touching and the child's fussiness (2) Significantly more mothers than fathers reported depression symptom levels in the clinical range. There was also a trend toward higher depressive symptoms among mothers when compared to fathers

				(3) Dysregulation and competence were significant unique predictors, whereas ratings of Internalizing behaviors approached significance
Eisenhower et al (2005), <i>Journal of Intellectual Disability Research</i> United States Level of Evidence: IV Emerging Theme: Stress	N=215 families with a 3-year-old child with or without developmental delay Age range of children: 3-5 years	Behavior problems, maternal well-being, cognitive delay	(1) Are there syndrome-related differences in behavior problems? (2) Are there syndrome-related differences in maternal well-being? (3) Is there syndrome-specific variance in maternal well-being, even after cognitive delay and behavior problems are accounted for?	(1) Typically developing children did not differ from children with Down syndrome, but were significantly less likely to have behavior problems in the clinical or borderline range than children with undifferentiated delays, autism, or cerebral palsy. Children with autism or cerebral palsy had more total behavior problems and more internalizing problems than children with Down syndrome or typically developing children, and children with autism had significantly more externalizing behavior problems than typically developing children (2) The autism group ranked highest in negative impact and maternal depression with cerebral palsy ranking second and down syndrome ranking lowest in impact (3) Child syndrome group had a negative impact above and beyond the contributions of behavior problems and cognitive level
Estes et al (2009), <i>Autism</i> United States Level of Evidence: IV Emerging Theme: Stress	N=74 mothers and their children (those with ASD and those who were developmentally delayed) Age range of children: from birth to 18 years, 11 months	Stress, psychological distress, problem behavior, living skills	(1) Parenting stress and psychological distress will be higher in mothers of children with ASDs (Autism Spectrum Disorder) compared with mothers in the DD (Developmentally Delayed) group (2) Children in the ASD group will have increased problem behavior and decreased daily living skills compared	(1) Mothers of children with ASDs showed significantly higher parenting stress scores than the mothers of children in the DD group. Mothers of children with ASDs also reported increased psychological distress (2) Children in the ASD group demonstrated higher levels of problem behaviors

			with the DD group (3) Child problem behaviors will be more strongly related to maternal parenting stress and psychological distress than child daily living skills within both the ASD and DD groups	(3) There was a stronger relationship between parenting stress and child problem behaviors in the DD group than in the ASD group
Hastings et al (2005), <i>Journal of Autism and Developmental Disorders</i> United Kingdom Level of Evidence: IV Emerging Theme: Stress	N=48 mothers and 41 father of pre-school children with autism Age range of children: 3-16 years	Stress	(1) Parental well-being may be substantially, but not necessarily exclusively, a function of the child with autism but also the mental health of their spouse (2) Paternal stress could be predicted from their report of their child's behavior problems and also from the mother's report (3) Partner mental health will add significantly to the prediction of parental stress from child variables	(1) Two significant differences were found, with mothers reporting more depression symptoms than fathers and also higher levels of positive perceptions than fathers (2) Mothers' ratings of their child's behavior problems were positively correlated with their ratings of anxiety, stress, and depression but not with positive perceptions. Father's ratings of their child's behavior problems were positively correlated with both their own and their partners' reported stress (3) Both child behavior problems and paternal depression made significant independent contributions to the prediction
Hoffman et al (2008), <i>Focus on Autism and Other Developmental Disabilities</i> United States Level of Evidence: IV Emerging Theme: Stress	N=72 mothers and their children with autism Age range of children: 4-16 years	Stress, autistic severity, sleep	Both mothers' sleep and children's autistic severity would predict mothers' reports of child-related stress.	Parents' sleep problems were significantly related to the child's sleep problems (bedtime resistance, sleep onset delay, sleep duration, sleep anxiety, night waking, parasomnias, and sleep disordered breathing) leading to mothers' reports of child-related stress.
Hoffman et al (2009), <i>Focus on Autism and Other</i>	N=104 mothers (and their children)	Stress, severity of autism symptoms	(1) To compare the stress levels reported by mothers of children with	(1) Mothers of children with autism reported higher levels of stress

<p><i>Developmental Disabilities</i></p> <p>United States</p> <p>Level of Evidence: IV</p> <p>Emerging Theme: Stress</p>	<p>Age range of children: 3-16 years</p>		<p>autism by using a larger number of participants for both groups than used in earlier studies of stress in mothers of children with developmental disabilities</p> <p>(2) Mothers of children with autism would report more stress on the Child Domain subscales of the PSI than mothers of typically developing children</p>	<p>(2) Mothers in the autism group reported higher levels of stress than did mothers of typically developing children in the community group</p> <p>(3) Mothers' reports of higher levels of stress related to the specific domains of their children's difficult behavior were also reported</p>
<p>Kayfitz et al (2010), <i>Journal of Applied Research in Intellectual Disabilities</i></p> <p>Canada</p> <p>Level of Evidence: IV</p> <p>Emerging Theme: Stress</p>	<p>N=23 mother/father pairs</p> <p>Age range of children: 5-11 years</p>	<p>Autism, fathers, mothers, positive experiences, stress</p>	<p>Mother and fathers experience the positive aspects of raising children with intellectual disabilities differently.</p>	<p>(1) Both mothers and fathers reported more positive experiences when they reported lower levels of parenting stress.</p> <p>(2) Mothers' parenting stress is related to fathers' experiences, but not vice versa.</p> <p>(3) Mothers reported more sensitivity and awareness of people with disabilities, greater acceptance of things in life, stronger bonds between family members, greater beliefs in the purpose of all people, and a larger circle of friends than did fathers.</p> <p>(4) Overall, mothers experienced more positive aspects of these children from an early age than did fathers and that these differences remained as these children grew older.</p>
<p>Larson (2005), <i>OTJR: Occupation, Participation, and Health</i></p> <p>United States</p> <p>Level of Evidence: VI</p>	<p>N=9 mothers</p> <p>Age range of children: 3-14 years</p>	<p>Routines, challenges</p>	<p>This study examined how routines were used and implemented by mothers parenting boys with autism and the challenges mothers faced in constructing sustainable daily routines.</p>	<p>Routines were essential building blocks in creating lifestyles for these families and a regularity that supported the family's emotional environment.</p> <ul style="list-style-type: none"> • Developing routines required considerable skill and

<p>Emerging Theme: Stress</p>				<p>focused on orderliness and the emotions of those participating</p> <ul style="list-style-type: none"> • Routines aided the mothers in providing predictable expectations for the child that smoothed the way for participation • Mothers suggested that regularity of routines provided a sense of security • The absolute adherence to some routines was a barrier to the improvisation required in daily life • Routines were used to provide regular expectations, ease transitions, and manage child's anxiety • When children had difficulties in performance, participation in daily routines was frustrating rather than comforting • Within the home environment, mothers felt they could more predictably manage a narrower set of circumstances that might trigger disruptions or discontent • The inability to tolerate change in weekly routines severely restricted any changes in schedules or participation in spontaneous or infrequent activities outside the home
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<p>Larson (2010), <i>Physical & Occupational Therapy in Pediatrics</i></p> <p>United States</p> <p>Level of Evidence: VI</p> <p>Emerging Theme: Stress</p>	<p>N=9 caregivers</p> <p>Age range of children: 3-14 years</p>	<p>Mother's well-being, daily activities, and caring routines</p>	<p>"Are there times of the day that things are likely to get stressful for you?"; "What creates the most stress in your life right now?"; "Are there any daily stresses which you experience?"; "What are the difficult things about raising a child with a disability?"</p>	<p>(1) Mothers repeatedly described an all-encompassing extreme vigilance to support their child's participation in everyday activities and to monitor their child's mood during activities, to keep the child "even".</p> <p>(2) Vigilance meant being in the "on mode" or on call 24/7 The "on mode" included hands on caregiving at all times of the day and night</p> <p>(3) This intense attending was experienced as tiring, leaving most of the mothers emotionally worn and physically depleted</p> <p>(4) Mothers sought intermittent breaks using babysitters or found calm moments in daily routines. Even with respite available, mothers often did not use it because of the emotional costs to the child, safety risks, the intense planning required, and inability of respite workers to deal with their child's needs</p> <p>(5) Vigilance allowed these mothers to precisely time their interventions to facilitate performance in daily activities, to assist at critical junctures in the child's social negotiations, and to monitor the current physical and social environmental dangers or triggers of behavioral episodes</p>
<p>Lee et al (2009), <i>Focus on Autism and Other Developmental Disabilities</i></p> <p>United States</p>	<p>N=135 parents</p> <p>Age range of children: 7-13 years</p>	<p>Parenting, stress coping, resources</p>	<p>(1) To determine if parents of children with HFASDs (High Functioning Autism Spectrum Disorders) report lower health-related QOL as compared to parents of children</p>	<p>(1) The Mental Health summary scale suggested that the QOL reported by these parents of children with HFASDs was significantly lower than that reported by participating parents</p>

<p>Level of Evidence: IV</p> <p>Emerging Theme: Stress</p>			<p>without a disability</p> <p>(2) To identify the relationship among various demographic and psychosocial variables and health-related QOL.</p>	<p>of typically developing children. Compared to parents of typical children, parents of children with HFASDs reported higher stress, lower levels of adaptive coping, and fewer resources</p> <p>(2) Within this group of parents with children with HFASDs, having a higher income and more children in the home was associated with a better physical health QOL. Income and number of children in the family were important demographic variables contributing to physical health QoL.</p>
<p>Myers et al (2009), <i>Research in Autism Spectrum Disorders</i></p> <p>United States</p> <p>Level of Evidence: VI</p> <p>Emerging Theme: Stress</p>	<p>N=493 Parents</p> <p>Age range of children: 2-21 years</p>	<p>Autism, parenting</p>	<p>“How has your child in the autism spectrum affected your life and your family’s life?”</p>	<p>CLUSTER 1—Stress</p> <p>Negative themes:</p> <ul style="list-style-type: none"> • Stress <p>Positive themes: None</p> <p>CLUSTER 2—Child’s behavior and demands of care and therapy</p> <p>Negative themes:</p> <ul style="list-style-type: none"> • Difficulty dealing with child’s behavior problems • Time demands for care and therapies • Sleep problems, exhaustion • Struggles with schools and services <p>Positive themes:</p> <ul style="list-style-type: none"> • New understanding regarding world of disabilities • Glad for child’s autism, uniqueness, would not change it if we could <p>CLUSTER 3—Impact on parents’ personal well being, work lives, and marital relationship</p>

				<p>Negative themes:</p> <ul style="list-style-type: none"> • Marital/couple strain (including divorce and separation) • Difficult emotions: grief, depression, guilt, blame • Mother's or Father's career or employment affected in negative way <p>Positive themes:</p> <ul style="list-style-type: none"> • Enriched our lives, a blessing, love for this child • Positive emotions: taught us compassion, tolerance, patience, joy • Learned to appreciate the little things, slow down • Spiritual life enriched • Marriage enriched <p>CLUSTER 4—Impact on the family as a whole, including siblings and extended family</p> <p>Negative themes:</p> <ul style="list-style-type: none"> • Siblings neglected, embarrassed, or hurt • Financial strain • Center of our lives, changed everything (negative tone) • Strained relations with extended family <p>Positive themes:</p> <ul style="list-style-type: none"> • Positive family adjustment and support • Positive impact on siblings <p>CLUSTER 5—Social isolation</p> <p>Negative themes:</p> <ul style="list-style-type: none"> • Restrictions on where we can
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				<p>go and what we can do</p> <ul style="list-style-type: none"> • Lost friends, no social life • Bad treatment by strangers and others <p>Positive themes: None</p>
<p>Phelps et al (2009), <i>Journal of Intellectual & Developmental Disability</i></p> <p>United States</p> <p>Level of Evidence: IV</p> <p>Emerging Theme: Stress</p>	<p>N=295 parents of children with autism spectrum</p> <p>Age range of children: 3-35 years</p>	<p>Stress, enrichment, posttraumatic growth</p>	<p>(1) Caregivers' stress scores and enrichment scores would have an inverse relationship; as stress increases, enrichment would decrease and vice versa</p> <p>(2) Parents would report higher levels of stress than enrichment for the majority of items on the Effects of the Situation Questionnaire</p> <p>(3) Stress reported would be positively correlated and enrichment would be negatively correlated with reported severity of symptoms. The more severe the child's disability the higher the stress and lower the enrichment reported</p> <p>(4) Stress reported would be positively correlated with posttraumatic growth scores, such that stress would serve as a trigger for posttraumatic growth in the lives of caregivers.</p>	<p>(1) Great enrichment with respect to friends, emotional well-being, and a sense of order/structure was significantly associated with having low stress on emotional well-being and sense of order/structure, but high stress with respect to relationships with family not living with the respondent</p> <p>(2) Great enrichment regarding view of self was significantly associated with low stress with respect to view of self, sense of order/structure, emotional well-being, and relationship with family not living with the respondent</p> <p>(3) There was no correlation between enrichment and reported severity of symptoms</p> <p>(4) Posttraumatic growth was not significantly correlated with total stress but was significantly associated with total enrichment</p>
<p>Phetrasuwan et al (2009), <i>Journal for Specialists in Pediatric Nursing</i></p> <p>United States</p> <p>Level of Evidence: IV</p>	<p>N=108 (106 biological mothers and 2 adoptive mothers)</p> <p>Age range of children: 3-10 years</p>	<p>Stress</p>	<p>(1) What are the sources of parenting stress in mothers of children with ASD?</p> <p>(2) What is the relationship between select maternal and child characteristics and parenting stress?</p> <p>(3) What is the relationship between</p>	<p>(1) Mothers with lower education levels and income reported higher overall parenting stress</p> <p>(2) There were no relationships either of the parenting stress variables and child characteristics of age, gender, and severity of ASD</p>

			parenting stress and maternal psychological status (depressive symptoms and psychological well-being)?	(3) Mothers with higher overall parenting stress reported more depressive symptoms. Mothers reporting more parenting stress also reported lower levels of well-being. Mothers with higher symptom-related parenting stress reported higher levels of depressive symptoms and lower levels of well-being.
Pottie et al (2008), <i>Journal of Pediatric Psychology</i> United States Level of Evidence: IV Emerging Theme: Stress	N=93 participants (60 mothers and 33 fathers) Age range of children: 4-12 years	Stress, social support, unsupportive interactions, mood	The purpose of this study was to investigate relationships between biweekly measures of daily parental stress, received social support, unsupportive interactions, and daily mood in mothers and fathers rearing a child with an ASD.	(1) Daily parenting stress significantly predicted lower levels of positive mood and higher levels of negative mood (2) More daily emotional support was significantly associated with higher levels of positive mood (3) Higher levels of daily unsupportive interactions were associated with lower levels of daily positive mood (4) Higher levels of parenting stress and more unsupportive social interactions predicted higher levels of positive mood (5) Support services did not significantly moderate the daily parenting stress-positive mood relationship but did moderate the daily parenting stress-negative mood relationship (6) Higher levels of disruptive child behaviors and elevated levels of daily stress predicted more daily negative mood.
Rao et al (2009),	N=12 mothers and 3	High functioning autism,	There is an impact of children with	(1) The source of increased parenting

<p><i>Behavior Modification</i></p> <p>United States</p> <p>Level of Evidence: IV</p> <p>Emerging Theme: Stress</p>	<p>fathers and siblings of 15 male children with HFA (High Functioning Autism) and N= 12 mothers and 2 fathers and siblings of 14 male children with no disorder (control group)</p> <p>Age range of children: 8-14 years</p>	<p>parental stress, sibling adjustment, family functioning</p>	<p>High Functioning Autism (HFA) on parental stress, sibling adjustment, and family functioning.</p>	<p>stress in the HFA (High Functioning Autism) group was associated with child behavioral factors that contributed stress to the parenting role</p> <p>(2) Analyses of the items that comprised this dimension separately revealed a trend toward a group difference in independence, with parents in the control group rating their families higher in independence than the parents in the HFA group</p> <p>(3) There was also a trend toward significance in active recreational orientation, operationalized as the extent of family participation in social and recreational activities, with JFA parents rating their families lower than control families.</p>
<p>Schieve et al. (2007), <i>Pediatrics</i></p> <p>United States</p> <p>Level of Evidence: VI</p> <p>Emerging Theme: Stress</p>	<p>N=78,305 children and their corresponding parent (96%) or other adult (4%).</p> <p>Age range of children: 4-17 years</p>	<p>Stress, autism severity, service needs</p>	<p>It was hypothesized that among parents of a child with autism, a number of factors might impact or intensify their stress level, including indicators of autism severity and/or current special service needs, factors related to severity, and factors related to socioeconomic status and culture that might impact resources, access to services, and care-seeking behavior.</p>	<p>(1) Parents reported feeling very close to their child</p> <p>(2) Parents reported being bothered by the things that their child did and feeling angry with their child</p> <p>(3) Parents reported difficulty in 3 areas: feeling their child was harder to care for than most same-aged children, being bothered by things their child does, and giving up more of their life than expected to meet their child's needs</p> <p>(4) More than 55% of parents of children with autism who recently needed special services were classified as having high aggravation.</p>
<p>Tobing et al (2006),</p>	<p>N=97 Participants were</p>	<p>Social support, competence,</p>	<p>(1) More social supports, greater</p>	<p>(1) A significant negative relation was</p>

<p><i>Journal of Family Social Work</i></p> <p>United States</p> <p>Level of Evidence: IV</p> <p>Emerging Theme: Social Support</p>	<p>mothers of children between the ages of 2 and 18 years with various forms of PDD</p> <p>Age range of children: 2-18 years</p>	<p>coping, parental stress, maternal distress</p>	<p>satisfaction with social support, greater parenting sense of competence</p> <p>(2) More coping strategies would decrease the strength of the relationship between the children's functional impairment/parenting stress composite and maternal psychological distress</p>	<p>found between satisfaction with social support and maternal psychological distress. There was a significant negative relation between total parenting sense of competence and maternal psychological distress</p> <p>(2) A significant positive relationship was found between child's functional impairment and parenting stress, and between children's level of functional impairment and maternal psychological distress. A significant positive relationship also was found between parenting stress and maternal psychological distress, which remained significant after controlling for the contribution of children's functional impairment</p>
<p>Wachtel et al. (2008), <i>Autism</i></p> <p>United States</p> <p>Level of Evidence: IV</p> <p>Emerging Theme: Stress</p>	<p>N=65 mothers and their children</p> <p>Age range of children: 2-28 months</p>	<p>Mother's emotional resolution status, child's diagnosis, parent-child interactions</p>	<p>Mothers' resolution status (measured dichotomously and on a continuum) with regards to their children's diagnoses would be related to observed parent-child interactions, independent of the contribution of demographic and child characteristics or maternal depressive symptoms.</p>	<p>(1) Of the three resolution variables, only emotional resolution was significantly associated with the parenting style</p> <p>(2) None of the demographic or child factors were significantly associated with supportive engagement</p>
<p>Woodgate et al. (2008), <i>Qualitative Health Research</i></p> <p>Canada</p> <p>Level of Evidence: VI</p> <p>Emerging Theme: Social Support</p>	<p>N=21 Parents</p> <p>Age of range children: Mean age = 7.6 years</p>	<p>Autism, parenting</p>	<p>Describe the lived experience of parents who have a child with autism.</p>	<p>Essence:</p> <p>(1) Society's lack of understanding</p> <p>(2) Missing a "normal" way of life</p> <p>(3) Feeling disconnected with the family</p> <p>(4) The unsupportive "system"</p> <p>Themes supporting essence:</p>

				<p>(1) Vigilant parenting</p> <ul style="list-style-type: none">• Acting sooner than later• Doing all you can• Staying close to your gut feelings <p>(2) Sustaining the self and family</p> <ul style="list-style-type: none">• Work toward a healthy balance• Cherish different milestones• Learn to let go <p>(3) Fighting all the way</p> <ul style="list-style-type: none">• Become more direct• Learn all they could• Educate others
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Appendix 5

Demographics

Participant	Child's Age (years)	Child's Gender	Parent/s Perceived Level of Function of the adolescent
Mother	11	Boy	High functioning
Mother	10 and 12	Boys	10-year-old: Severe 12-year-old: High functioning
Mother	18	Boy	High functioning
Father and mother	18	Girl	Severe
Father and mother	13	Boy	High functioning
Mother	18	Boy	Severe
Mother	12	Girl	High functioning
Mother	12	Boy	High functioning
Mother	13	Girl	High functioning
Mother	11	Boy	High functioning

The invariant horizons or significant statements point to the unique qualities of an experience, those that stand out. The student researcher reduced the description of the experience of managing the healthcare needs of adolescents with ASD to the following core horizons (Moustakas, 1994).

Selected Significant Statements

- She's not only autistic, she's epileptic...it was time consuming with that and also taking care of her medical needs.
- Masturbation was hard on me. That was really hard for me because I didn't know if someone else was touching her too because she couldn't tell me or if she had been abused. We had to teach her to go to her room to touch herself because she would touch her breasts and privates in public.
- I wish there was more and they don't know what to do. Still like they're used to working with normal children so.
- Hygiene is an issue. I think it is with all kids that age and I really have to stay on him about brushing his teeth, taking a shower, and ... will be in the shower for 20 minutes and not a drop of soap will touch his body.
- Um, sleep is probably the biggest, is one of the biggest areas, the biggest stressor. He'll just wander around the yard at night and you'll just see him looking in our window.
- The hard part is just keeping him away from food he shouldn't eat.
- They [dentist] have to completely but him to sleep. He won't even get in the chair awake.
- I don't think anybody really knows what truly is going on with him. It's just they medicate the symptoms.
- Some doctors acted like we were just totally stupid.
- He wants to be like the other kids so he quit taking his meds.
- Somebody dared my son to snort a whole pill of OxyContin and he did and it almost killed him.
- Due to her gastrointestinal problems, she will begin stimming.
- He has anxiety and depression and his behavior often escalates when he is upset.
- They [outbursts] became more violent.

- It was at the point where he wanted to hurt himself I was told “well we can’t do anything until he hurts himself or somebody.” And I’m like “are you kidding me? You’re telling me that until he commits suicide, then you’ll listen to me?” So that was a little frustrating
- Um, I was really worried you know to find good health care and we’d, I don’t want to use the word “quack” but we have been to some people that I thought you know, I’m not the most educated person but I have educated myself on every single, tiny little diagnosis they gave him.
- Um, my husband and I tend to ask a lot of questions and I think it’s because we educate ourselves about the medications he’s on too. I want to know the side effects. I want to know is this going to make him sterile. Um, you know, is this going to affect his liver, what about heart palpitations.
- Um, a lot of mental health.
- First thing I do when I mention that you know I think it’s time to go see a doctor and his first question is “am I going to get a shot?” He obsesses. He’ll be so anxious and nervous that it will ruin his day.
- I mean I’m always the one who takes my son to the physician always, because I know what questions to ask.
- It’s kind of conflicted because I don’t want to overmedicate my child, however, the medication is going to help him and if it’s something that’s going to be very beneficial to him, then I am all for it.
- I’ve had my bad experiences obviously with the neurologist and I’ve had really good experiences, especially within the mental health industry and the help that I’ve received from them.
- There’s no consistency in care.
- He is often sick...the medications, we don’t know if they’re you know, fighting the immunity or helping him.
- Getting him to take medicine is another issue in its self and he doesn’t want to take any kind of medicines. He’s just leery and suspicious.
- He wakes up as a different kid and it’s very frustrating for me because he’s on an enormous amount of medication.
- I read those medical warnings about suicidal risk and all that kind of stuff and it just sets me in a panic.
- I don’t know what [role] the drug companies play in all of that but I’m sure that there’s more pressure for people to try drugs that maybe shouldn’t be trying them.
- You have to be very specific [with the child]. So that has been a very big challenge.
- It often takes several people to hold him down if he needs an injection.
- It’s I feel like a lot of times they’re practicing medicine. That he’s the guinea pig.
- I’ve taken my son to a doctor who really didn’t know how to deal with him, so we couldn’t go back.

- Frustration was we felt like we were being taken advantage of.
- So it was very frustrating for me I guess to have a doctor who sees her but doesn't really know her, look at her chart and think 'oh she's all drama', and not take that moment legitimate for what it was.
- I really wish we had a pediatrician that worked hand-in-hand with us for all these kinds of things. Instead of see her as a whole person and not from this.
- So pretty much just from the time I just got frustrated with the whole medical community, kind of feeling like they were blowing me off and were not just helping me so I kind of stopped going down that road.
- But to me the whole mental health is really the... again like I said, I feel like the schools almost do a better job with managing all of that than the medical community.
- I don't think the system is working well but I think we've figured out where we need to be in it, but it certainly took several years.
- They [dentist] have to completely put him to sleep. He won't even get in the chair awake.
- It is very difficult to take them to the doctor's office or get him... I mean I remember having a meltdown, he had a meltdown and I had a meltdown at HP... because you know it's just so hard to manage him in a doctor's office.
- He's a huge safety risk; he doesn't understand safety or the concepts of safety. He doesn't understand if he stands in the road flapping his hands he could get hit by a car and die.
- I heard laughter and found my son climbing out of his bedroom window onto the roof.
- The drugs [illegal ones] worry me the most.
- He has an extremely high threshold for pain.
- He does have gastric problems. I don't know if that's from the medicine or just growing.
- He makes terrible decisions in order to be accepted. I know that he drinks and smokes pot.
- She is lactose intolerant and cannot eat certain foods without having behavior problems.
- She has started her menstrual cycle and I have noticed huge, huge mood swings. We started noticing difficult behaviors.
- When a person hurts my son relationally and emotionally he really hurts and he will hate that person.
- That was probably the biggest pain was toilet training.
- His thing now is he's more aggressive.
- We do have very big concerns of what happens to her as she starts becoming a teen and her body is really changing.
- She exercises a lot like really excessively and she's also very, very concerned about what she eats. She doesn't want to eat anything that's too high in fat or you know in any way unhealthy.

- She's not only autistic, she's epileptic and it is time consuming with that, so with taking care of all her medical needs I had to quit work.
- He has jumped out of cars while they were moving and that was scary.
- We almost hit bankruptcy with medication and doctors and hospitals and therapists and nothing helped.
- I need help.
- We cannot do it without services or resources out in the community.
- I feel like I'm a fighter and I have to investigate it myself.
- There again you have to beg and ask for it [medical services]. It's not just somebody advertising, "Hey we do this for autism."
- Help me as a parent; help my husband as a parent.
- Educate us.
- None of the information or literature covers adolescents with ASD.
- I just, you get so tired. You can only do so much.
- So a lot of these are learning lessons for me.
- The insurance wasn't covering all of our medical stuff and we couldn't find anybody in this area that would take our insurance.
- I don't feel that there have been enough done in different areas in adolescents or in the younger ages to know how to adequately treat these children.

Appendix 6-2

Meaning Units or Themes

From the invariant constituents or significant statements, the student researcher, using phenomenological reflection and imaginative variation, constructs thematic portrayals of the experience of parents managing the healthcare needs of adolescents with ASD. The following verbatim excerpts represent her clustering of the delimited meanings or horizons into core themes. They represent distinctive processes that are inherent in and often sequences of managing those healthcare needs (Moustakas, 1994).

Themes or Meaning Units and Evidence

Themes or Meaning Units	Evidence in Parents' Statements
<i>Parent's Need for Help:</i> Concerns about medications	<p>“He is often sick. ...the medications, we don't know if they're you know, fighting the immunity or helping him.”</p> <p>“He just wants to be like the other kids so he quit taking his meds.”</p> <p>“It's kind of conflicted because I don't want to overmedicate my child, however, the medication is going to help him and if it's something that's going to be very beneficial to him, then I am all for it.”</p> <p>“Getting him to take medicine is another issue in its self and he doesn't want to take any kind of medicines. He's just leery and suspicious.”</p> <p>“He wakes up as a different kid and it's very</p>

	<p>frustrating for me because he's on an enormous amount of medication.”</p> <p>“Um, my husband and I tend to ask a lot of questions and I think it's because we educate ourselves about the medications he's on too. I want to know the side effects. I want to know is this going to make him sterile. Um, you know, is this going to affect his liver, what about heart palpitations.”</p> <p>“I read those medical warnings about suicidal risk and all that kind of stuff and it just sets me in a panic”</p> <p>“I don't know what [role] the drug companies play in all of that but I'm sure that there's more pressure for people to try drugs that maybe shouldn't be trying them.”</p> <p>“Getting him to take medicine is another issue in its self and he doesn't want to take any kind of medicines. He's just leery and suspicious.”</p> <p>“You have to be very specific [with the child]. So that has been a very big challenge.”</p> <p>“It often takes several people to hold him down if he needs an injection.”</p>
<p><i>Parent's Need for Help:</i> Frustrations with healthcare services</p>	<p>“I've had my bad experiences obviously with the neurologist and I've had really good experiences, especially within the mental health industry and the help that I've received from them.”</p> <p>“There's no consistency in care.”</p> <p>“I don't think anybody really knows what truly is going on with him. It's just they medicate the symptoms.”</p> <p>“Some doctors acted like we were just totally stupid.”</p> <p>“It was at the point where he wanted to hurt</p>

himself I was told “well we can’t do anything until he hurts himself or somebody.” And I’m like “are you kidding me? You’re telling me that until he commits suicide, then you’ll listen to me?” So that was a little frustrating”

“Um, I was really worried you know to find good health care and we’d, I don’t want to use the word “quack” but we have been to some people that I thought you know, I’m not the most educated person but I have educated myself on every single, tiny little diagnosis they gave him.”

“It’s I feel like a lot of times they’re practicing medicine. That he’s the guinea pig.”

“I’ve taken my son to a doctor who really didn’t know how to deal with him, so we couldn’t go back.”

“Frustration was we felt like we were being taken advantage of”

“So it was very frustrating for me I guess to have a doctor who sees her but doesn’t really know her, look at her chart and think ‘oh she’s all drama’, and not take that moment legitimate for what it was”

“I really wish we had a pediatrician that worked hand-in-hand with us for all these kinds of things. Instead of see her as a whole person and not from this.”

“So pretty much just from the time I just got frustrated with the whole medical community, kind of feeling like they were blowing me off and were not just helping me so I kind of stopped going down that road”

“But to me the whole mental health is really the... again like I said, I feel like the schools almost do a better job with managing all of that than the medical community”

	<p>“I don’t think the system is working well but I think we’ve figured out where we need to be in it, but it certainly took several years.”</p> <p>“First thing I do when I mention that you know I think it’s time to go see a doctor and his first question is “am I going to get a shot?” He obsesses. He’ll be so anxious and nervous that it will ruin his day.”</p> <p>“They [dentist] have to completely but him to sleep. He won’t even get in the chair awake. I had to take him to the doctor and I took him to the emergency room because his anger was so out of control.”</p> <p>“It is very difficult to take them to the doctor’s office or get him...I mean I remember having a meltdown, he had a meltdown and I had a meltdown at HP...because you know it’s just so hard to manage him in a doctor’s office.”</p>
<p><i>Parent’s Need for Help:</i> Recognizing secondary health issues</p>	<p>“Um, a lot of mental health.”</p> <p>“He’s a huge safety risk; he doesn’t understand safety or the concepts of safety. He doesn’t understand if he stands in the road flapping his hands he could get hit by a car and die.”</p> <p>“I heard laughter and found my son climbing out of his bedroom window onto the roof.”</p> <p>“Hygiene is an issue. I think it is with all kids that age and I really have to stay on him about brushing his teeth, taking a shower, and ... will be in the shower for 20 minutes and not a drop of soap will touch his body. We have to go in there and like physically peek to make sure that he’s putting soap on his body and brushing his teeth, using deodorant.”</p> <p>“Um, sleep is probably the biggest, is one of the biggest areas, the biggest stressor. He’ll just wander around the yard at night and you’ll just see him looking in our window.”</p>

	<p>“The hard part is just keeping him away from food he shouldn’t eat.”</p> <p>“The drugs [illegal ones] worry me the most.”</p> <p>“He has an extremely high threshold for pain.”</p> <p>“He does have gastric problems. I don’t know if that’s from the medicine or just growing.”</p> <p>“He has anxiety and depression and his behavior often escalates when he is upset.”</p> <p>“They [outbursts] became more violent.”</p> <p>“She’s epileptic and often has sleep problems.”</p> <p>“Masturbation was hard on me. That was really hard for me because I didn’t know if someone else was touching her too because she couldn’t tell me or if she had been abused. We had to teach her to go to her room to touch herself because she would touch her breasts and privates in public.”</p> <p>“He makes terrible decisions in order to be accepted. I know that he drinks and smokes pot.”</p> <p>“She is lactose intolerant and cannot eat certain foods without having behavior problems.”</p> <p>“She has started her menstrual cycle and I have noticed huge, huge mood swings. We started noticing difficult behaviors.”</p> <p>“Somebody dared my son to snort a whole pill of OxyContin and he did and it almost killed him.”</p> <p>“When a person hurts my son relationally and emotionally he really hurts and he will hate that person.”</p> <p>“That was probably the biggest pain was toilet training”</p>
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	<p>“His thing now is he’s more aggressive.”</p> <p>“We do have very big concerns of what happens to her as she starts becoming a teen and her body is really changing”</p> <p>“She exercises a lot like really excessively and she’s also very, very concerned about what she eats. She doesn’t want to eat anything that’s too high in fat or you know in any way unhealthy”</p> <p>“Due to her gastrointestinal problems, she will begin stimming.”</p> <p>“She’s not only autistic, she’s epileptic and it is time consuming with that, so with taking care of all her medical needs I had to quit work.”</p> <p>“He has jumped out of cars while they were moving and that was scary.”</p>
<p><i>Parent’s Need for Help:</i> Need for specific resources</p>	<p>“I mean I’m always the one who takes my son to the physician always, because I know what questions to ask.”</p> <p>“We almost hit bankruptcy with medication and doctors and hospitals and therapists and nothing helped.”</p> <p>“I need help”</p> <p>“We cannot do it without services or resources out in the community.”</p> <p>“I wish there was more [services] and they don’t know what to do”</p> <p>“I feel like I’m a fighter and I have to investigate it myself.”</p> <p>“There again you have to beg and ask for it [medical services]. It’s not just somebody advertising “hey we do this for autism”.”</p>

	<p>“Help me as a parent; help my husband as a parent.”</p> <p>“Educate us.”</p> <p>“None of the information or literature covers adolescents with ASD”</p> <p>“I just, you get so tired. You can only do so much”</p> <p>“So a lot of these are learning lessons for me”</p> <p>“The insurance wasn’t covering all of our medical stuff and we couldn’t find anybody in this area that would take our insurance.”</p> <p>“I don’t feel that there have been enough done in different areas in adolescents or in the younger ages to know how to adequately treat these children.”</p>
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Appendix 6-3

Textural and Structural Descriptions for Overall Research

The final step of Moustakas' phenomenological model requires an integration of the composite textural and composite structural descriptions, providing a synthesis of the meanings and essences of the experience (Moustakas, 1994).

The experience of caring for the healthcare needs of an adolescent child with autism was described by parents as quite challenging and frustrating. Parents also reported the experience to be difficult, stressful, and time consuming.

When talking about managing the adolescent's healthcare needs, parents spoke about their concern with medications. Parents often stated that they were worried about the types of medications their adolescent was prescribed. There were concerns regarding the various side effects that might be experienced. There were also concerns about the difficulty in getting their adolescent to take medications. Parents of older adolescents expressed that it was difficult getting their adolescent to be compliant in taking their medication because the adolescent didn't want to be different from his or her peers. Some parents stated that medication compliance was difficult because their adolescent seemed afraid to take prescribed medication; while others stated that they had to be very exact in their wording in order for the adolescent to understand their' directions in taking medication. Finally, there was concern expressed about the role that pharmaceutical companies played in the prescribing of medications to their adolescents with

ASD: there was anxiety related to whether or not their children were being treated as “guinea pigs”.

Parents voiced their frustrations related to health care services. They stated that they had little faith in the healthcare community due to lack of general knowledge about ASD. Parents were also frustrated in the type of immediate care that their adolescent received from primary care providers. Many parents voiced concerns about how they were perceived as parents and how their adolescents were treated.

All parents voiced concerns about the number of secondary health issues that their adolescent experienced. These health issues involved seizures, constipation and diarrhea, celiac disease, and lactose intolerance. Parents also addressed problems with personal hygiene, sleep, and safety. They spoke of having to assist their adolescent in personal hygiene practices. They also spoke of having to give step-by-step instructions when explaining the process of bathing and brushing teeth. Sleep disturbances also created problems for the parents as the adolescent would get up during the night and wander around the house making sleep difficult for the parent and siblings. Safety was also voiced as a concern as the adolescent lacked the ability to understand the concepts of harm and danger. Some parents of older adolescents voiced concerns about dealing with their child’s hormonal changes and the effects this had on the adolescent’s behavior. Several spoke of their uneasiness with issues surrounding menstruation. Others spoke about concerns dealing with masturbation and unsafe sexual behavior as well as other risky behaviors. Several parents talked about their adolescent’s inability to make good choices in dressing attire and their inability to recognize problems that could ensue once secondary sexual characteristics started to develop. Finally, parents spoke about the challenges in dealing with specific medical procedures such as the adolescent receiving an injection, a blood drawing, or dental care. They

spoke on the importance of preparing the adolescent before any medical procedure. Some procedures such as dental care required that the adolescent be anesthetized.

Parents voiced a concern about the lack of services in general for adolescents with ASD and repeatedly spoke about the need for specific resources and assistance in dealing with their adolescent's healthcare issues. They talked about the specific need for educating not only themselves but others as well. It was noted that the mothers were primarily the ones who took responsibility for the healthcare of their adolescent.

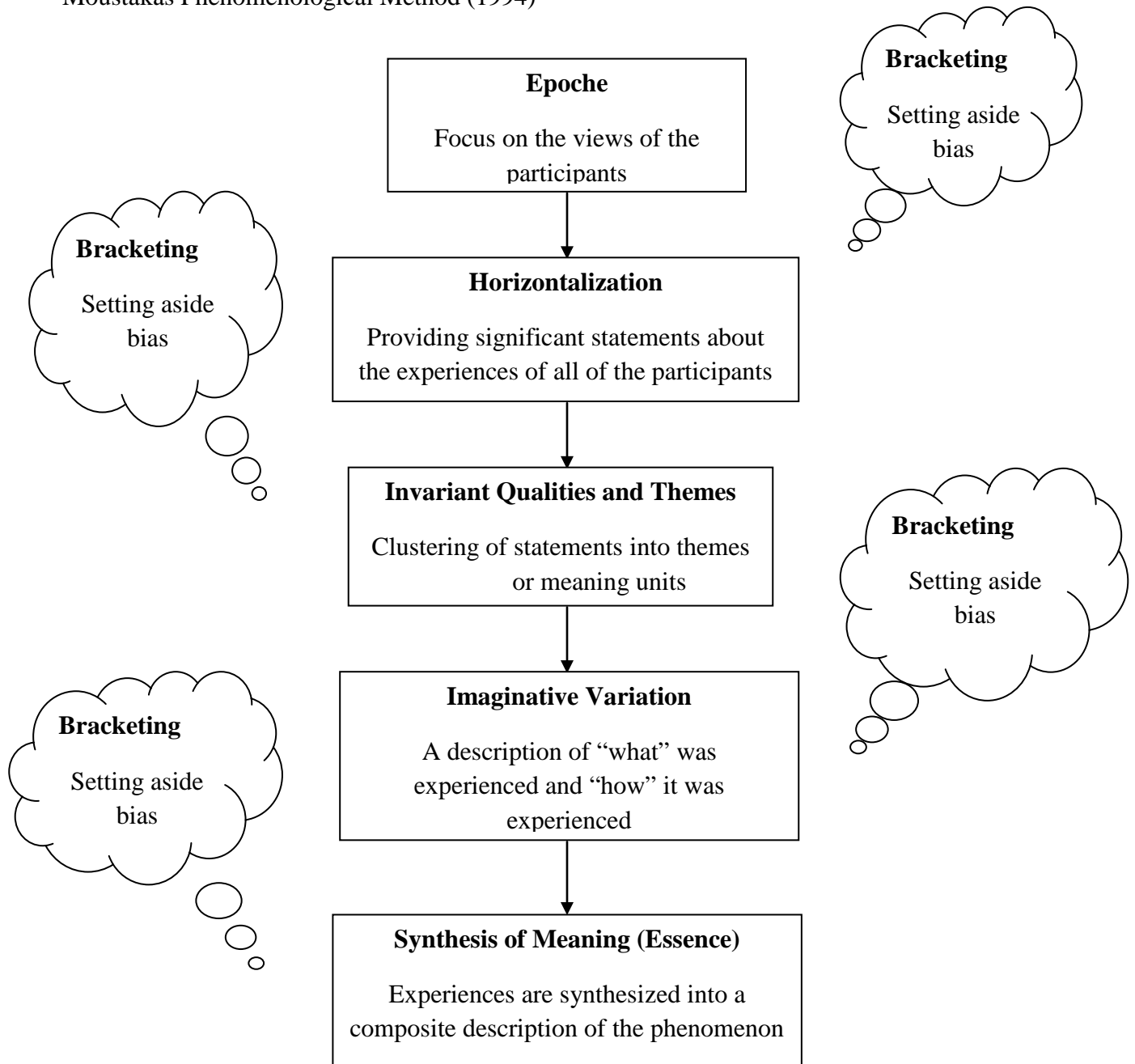
Appendix 6-4

The Essence of the Experience

The textural and structural descriptions of the experiences are then synthesized into a composite description of the phenomenon through the research process referred to by Moustakas (1994, p, 100) as “intuitive integration.” This description becomes the essential, invariant structure of ultimate “essence” which captures the meaning ascribed to the experience.

The essence of the phenomenon was that parents need help in order to meet the healthcare needs of their adolescents with ASD. This essence is revealed in the four themes that were distilled during the integration of the individual participant’s structural and textural statements: concern with medications, frustrations with healthcare services, recognizing secondary health issues, and the need for resources and services.

Moustakas Phenomenological Method (1994)



Curriculum Vitae

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Assistant Professor, Eastern Mennonite University School of Nursing, Harrisonburg,
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2011

Pediatric clinical instructor, James Madison University School of Nursing, Harrisonburg,
Virginia

2008 – present

Instructor, Information Literacy in Health Care, Virginia Commonwealth School of
Nursing,

Richmond, Virginia

2009 – present

Teaching Assistant, Nursing of Adults, Virginia Commonwealth School of Nursing,
Richmond,

Virginia
2010

Instructor, Special Topics in HHS SP10 (Autism Spectrum Disorders), James Madison University, Harrisonburg, Virginia
2010

Clinical instructor, Technologies of Nursing Practice, Virginia Commonwealth School of Nursing,
Richmond, Virginia
Summer 2010

Clinical Lab Instructor, Nursing of Women, Virginia Commonwealth School of Nursing,
Richmond, Virginia
Fall 2010

PUBLICATIONS

Strunk, J.A. (2008). The effects of school-based health clinics on teenage pregnancy and parenting outcomes: an integral literature review. *The Journal of School Nursing, 24*(1), 13-20.

Strunk, J.A. (2009). School nurses' knowledge of autism spectrum disorders. *The Journal of School Nursing, 25*(6), 445-452.

Strunk, J.A. and Rocchiccioli, J.T. (2010). Meningococcal meningitis: an emerging infectious disease. *Journal of Community Health Nursing, 27*(1), 51-58.

Strunk, J.A. (2010). Respite care for families of special needs children: a systematic review. *Journal of Developmental and Physical Disabilities, 22*(1), 1-16.

Phillips-Pula, L, Strunk, J.A., & Pickler, R. (2010). Understanding phenomenological approaches to data analysis. *Journal of Pediatric Health Care* (to be published in the Jan/Feb 2011 issue).

Townsend-Rocchiccioli, J., Strunk, J., & Sanford, J. (2011). The aging Hispanic individual in America: Challenges for nurses in a stressed healthcare environment. *Medical-Surgical Nursing*.

REFEREED PUBLICATIONS

Townsend-Rocchiccioli, J., Strunk, J., & Jagello, K. (Submitted for review, February 2011). Perceptions of diabetes in Malta: A qualitative study. *Journal of Diabetes Nursing*.

DISSERTATION

Strunk, J.A. (April 2011). Managing the Healthcare Needs of Adolescents with Autism Spectrum Disorder: A Parent's Experience. Virginia Commonwealth University School of Nursing Doctoral Program.

PRESENTATIONS

Strunk, J.A. (2008). Getting to the Heart of the Matter. Presented at Pi Mu Day at James Madison University

Strunk, J.A. (2008). School Nurses Working Knowledge of Children with Autism Spectrum Disorders. Presented at the School Health Institute at Longwood College

Strunk, J.A. (2008). Eating Patterns in School Age Children and Their Impact on Childhood Obesity. Presented at the Institute of Health in Malta

Strunk, J.A. (2008). Eating Patterns in School Age Children and Their Impact on Childhood Obesity. Poster presentation at James Madison University

Strunk, J.A. (2009). Maternal Well-being and Preterm Infant Outcomes. Poster presentation at James Madison University

Strunk, J.A. (2009). Maternal Well-being and Preterm Infant Outcomes. Poster presentation at SNRS in Austin, Texas

Strunk, J.A. (2010). Maternal Well-being and Preterm Infant Outcomes. Poster presentation at Virginia Commonwealth University

Strunk, J.A. (2010). Children with Autism Spectrum Disorder and Its Effects on Parents: An Integrative Review. Poster presentation at SNRS in Jacksonville, Florida.

Strunk, J.A. (2011). Children with Autism Spectrum Disorder and Its Effects on Parents: An Integrative Review. Presented at Pi Mu Day, James Madison University

GRANTS AND FELLOWSHIPS

RMH Foundation (Getting to the Heart of the Matter)

AWARDS AND HONORS

Vida Huber Spirit of Nursing Award

Southern Nursing Research Society Outstanding Student Poster 2011

PROFESSIONAL MEMBERSHIPS

Pregnancy Prevention Coalition Board Member
Hand in Hand, Rockingham Memorial Hospital

National Association of School Nurses

Virginia Association of School Nurses

Sigma Theta Tau Honor Society

Golden Key International Honor Society

National League of Nurses

National Institute of Nursing Research

National Association of Palliative Care Nurses

American Association of Nurses

Virginia Association of Nurses

Southern Nursing Research Society