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Filipino American Parental Beliefs and Perceptions about Managing Care for Children and Adults with Autism Spectrum Disorder

A dissertation submitted in partial satisfaction of the
requirements for the degree Doctor of Philosophy
in Nursing

by

Sharee Bantad Anzaldo

2020

ABSTRACT OF THE DISSERTATION

Filipino American Parental Beliefs and Perceptions about Managing Care for Children and Adults with Autism Spectrum Disorder

by

Sharee Bantad Anzaldo
Doctor of Philosophy in Nursing
University of California, Los Angeles, 2020
Professor Felicia S. Hodge, Chair

Autism spectrum disorder (ASD) is a developmental disability that affects 1 in 54 children in the United States. This developmental disability impacts an individual's behavior, communication patterns, and social interactions. ASD strikes 17.9 per 1,000 Asian American and Pacific Islander children in the United States. A dearth of knowledge exists about ASD within the Filipino American community. Shame and stigma related to ASD negatively affect how Filipino Americans perceive the developmental disability, and contribute to underreporting and delayed intervention.

Grounded theory was utilized to explore Filipino American cultural beliefs and perceptions about ASD, describe how Filipino American parents manage care for children and adults with ASD, and generate an explanatory framework about processes involved in Filipino American parental management of care for children and adults with ASD. Social constructionism was used as a theoretical framework and symbolic interactionism was used as a philosophical underpinning.

Research participants partook in a personal interview to capture cultural beliefs and perceptions about ASD using Kleinman's Explanatory Model of Illness and explore parental management of children and adults with ASD. Demographic information and levels of acculturation and parent adjustment to illness were also collected. Coding processes, memos, reflexive journals, diagrams, and field notes were utilized for data analysis.

Eighteen participants enrolled in the research study. Traditional Filipino cultural values and generational differences influenced beliefs and perceptions about ASD. Causal beliefs of ASD were attributed to environmental factors, medical conditions, pharmaceutical products, prenatal events, genetic history, and/or superstitious beliefs. Management of ASD involved recognizing signs and symptoms of ASD, seeking help, learning about ASD, organizing daily schedules, integrating into social settings, de-escalating challenging behavior, incorporating self-care, worrying about the future, navigating cultural awareness, accepting the diagnosis, defining parenting role, and being an advocate.

Filipino American cultural beliefs and perceptions influence how ASD is understood, perceived, and managed. Integration of culturally tailored screening tools, educational programs, and interventions are essential to ensure that nurses provide comprehensive, holistic care for Filipino Americans with ASD. Raising awareness about ASD in the Filipino American community is necessary to further understand the developmental disability, which has no cure, throughout the lifespan.

The dissertation of Sharee Bantad Anzaldo is approved.

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Donald E. Morisky

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2020

DEDICATION

To my parents, Elpidio and Rosalia Anzaldo, for their unwavering support, innumerable sacrifices, and unconditional love.

TABLE OF CONTENTS

LIST OF TABLES

ACKNOWLEDGEMENTS

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My passion for nursing research was fueled through clinical practice at CHLA. Leticia Boutros, my manager, was committed to not only helping me thrive as a pediatric nurse, but also as a nurse researcher. Her support for nursing education is unparalleled. I am also grateful for Catherine Foster, who introduced me to the perianesthesia nursing specialty. The wisdom of my coworkers, LaToya Fowler, Jeanne Kasukabe Lee, and Sara Yee, impacted my life in many ways. Through the doctoral program, I crossed paths with Allan Cresencia and Megan Guardiano, who are the epitome of friendship. Their insight and encouragement, coupled with their humor and generosity, made this educational journey memorable.

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VITA

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PUBLICATIONS

Harrington, C., Anzaldo, S., Burdin, A., Kitchener, M., & Miller, N. (2004). Trends in certificate of need and moratoria programs for long term care providers. *Journal of Health and Social Policy, 19*(2), 31-58.

CHAPTER ONE

INTRODUCTION

Autism Spectrum Disorder

Autism spectrum disorder (ASD) is a major public health concern that strikes approximately one out of 54 children in the United States (Centers for Disease Control and Prevention [CDC], 2020b). ASD is a neurodevelopmental disability that impairs an individual's behavioral patterns, communication patterns, and social interactions (CDC, 2020e; National Institute of Neurological Disorders and Stroke [NINDS], 2020). This developmental disability impacts how individuals behave, communicate, learn, problem-solve, socialize, and think (CDC, 2020e). As a spectrum, the symptomology of this developmental disability ranges from mild to severe (NINDS, 2020). Those diagnosed with ASD exhibit varying levels of independence in their activities of daily living, as some can function more independently, whereas others may require assistance from caregivers (CDC, 2020e). Although treatments are available to ameliorate the symptoms of ASD, there is currently no cure for this developmental disability (CDC, 2019d; NINDS, 2020). Enrollment in early intervention programs helps optimize development and improve symptoms in those diagnosed with ASD (CDC, 2019d; NINDS, 2020).

Research Problem

With the steady increase of diagnosed ASD cases over the past decade, it is important to place the developmental disability within a cultural context. Beliefs and perceptions about health and illness in the Filipino culture influence help-seeking behaviors, and subsequently affect parenting children with a chronic illness or disability. There is a paucity of literature exploring ASD within the context of the Filipino American culture and the Asian American/Pacific

Islander population at-large (Nadal & Monzones, 2011; Won, Krajicek, & Lee, 2004). Although little research on ASD has been conducted with this population in the United States, research reports ASD affects over half a million children in the Philippines (Autism Society Philippines, 2014; Kopetz & Endowed, 2012; Nadal & Monzones, 2011).

Of those affected in the Philippines, only a small subset (two percent) receive care for the disorder (Autism Society Philippines, 2014). Filipino parents may not report their child's ASD for several reasons: (1) lack of awareness of the developmental disability; (2) financial hardship hindering health care access; and (3) disinterest in child's behavioral or developmental changes (Autism Society Philippines, 2014; Nadal & Monzones, 2011). In addition, parents residing in the United States may fail to report ASD due to perceived shame and stigma associated with raising a child with a developmental disability (Nadal & Monzones, 2011). Nadal and Monzones (2011) suggested that shame and stigma intensify among Filipino American immigrants "in search of the American Dream" (p. 55).

Prevalence

The prevalence of ASD among Asian/Pacific Islanders residing in the US has been examined by various organizations. Most recently, the Autism and Developmental Disabilities Monitoring Network (ADDM) Network found that ASD affects 11.3 per 1,000 Asian American/Pacific Islander children (CDC, 2020b). A study conducted by Windham et al. (2011) found that the prevalence of ASD in Asian, non-Hispanic children was comparable to white non-Hispanic children eight years or younger—5.2/1,000 children and 6.0/1,000 children, respectively, in the San Francisco Bay Area.

The California Department of Developmental Services (DDS) also collected data on ASD based on individuals who utilized their services (Cavagnaro, 2007). This descriptive study noted an increased prevalence of ASD as compared to other chronic conditions, such as Down syndrome, childhood cancer, and type 1 diabetes, warranting data collection to determine ASD trends in California (Cavagnaro, 2007). According to this report, 8.9 percent of Asians and 3.3 percent of Filipinos with ASD were served by the DDS (Cavagnaro, 2007). The average age of all individuals in this study was 13.6 years (Cavagnaro, 2007).

Lastly, a study investigated the role of maternal nativity, race, and ethnicity in children born and diagnosed with ASD in the county of Los Angeles, California (Becerra et al. 2014). This study focused on minority groups with ASD, specifically Asian/Pacific Islanders, Hispanics, and African Americans/Blacks (Becerra et al., 2014). California birth certificates were matched with DDS records of children with: (1) a primary diagnosis of ASD; (2) a primary diagnosis of ASD with a secondary diagnosis of intellectual disability; (3) a primary diagnosis of ASD with varying degrees of expressive language impairment (impaired versus less impaired); and (4) a primary diagnosis of ASD with varying degrees of emotional outburst severity (severe versus less severe) (Becerra et al., 2014). Results indicated for Philippine-born mothers suggested an increased adjusted rate of 25 percent of having a child with a primary ASD diagnosis, an increased crude rate of having a child with a primary ASD and secondary intellectual disability diagnosis, an increased risk of a primary ASD diagnosis with impaired expressive language, and a slightly increased risk of a primary ASD diagnosis with less severe emotional outbursts (Becerra et al., 2014). Nearly a third (30%) of Filipino mothers are reportedly employed in healthcare professions, considered as a high-risk occupation for potential exposure to communicable or infectious diseases (Becerra et al., 2014; Terrazas & Batalova, 2010). With the association of maternal infections, such as influenza or fevers, to changes in fetal brain development, the authors speculate that there is a link between a child's diagnosis of

ASD and maternal occupation in Filipino mothers, thus a maternal diagnosis of influenza or fevers during pregnancy may elevate the unborn child's risk of developing ASD early in life (Atladóttir et al., 2010; Atladóttir, Henriksen, Schendel, & Parner, 2012; Becerra et al., 2014; Patterson, 2009; Zerbo et al., 2013).

Prevalence of ASD increased over the past few decades in the United States. According to Boat and Wu (2015), from a historical context, ASD was not recognized as a category for special education eligibility until 1991. Previously, those children with ASD may have been receiving special education classes through another category, such as intellectual disability or developmental disability (Boat & Wu, 2015). Once ASD was recognized, the number of children receiving special education classes under intellectual disability and developmental disability declined (Boat & Wu, 2015). Additionally, pediatric health care has advanced through the inclusion of well-child visits, which include routine developmental screenings, development of valid and reliable screening and diagnostic tools for ASD, more specialized training for clinicians working with the ASD population, and improvements in diagnostic processes, where children may receive more than one developmental disability diagnosis (Boat & Wu, 2015). Furthermore, ASD has been more visible in the media, which also led to increased advocacy efforts to raise awareness about the developmental disability in the United States (Boat & Wu, 2015).

Filipino American Culture

The 2010 U.S. Census found that Filipinos comprise the second-largest Asian group in the United States—preceded by the Chinese, the largest Asian group, and followed by Asian Indians, the third largest Asian group (Hoeffel, Rastogi, Kim, & Shahid, 2012). Many studies about ASD have focused on the Asian American population collectively. As a group, the Asian population includes individuals who identify as those from the "Far East, Southeast Asia, or the Indian Subcontinent" (Hoeffel et al., 2012, p. 2). Application of research findings may be limited because each ethnic group has a distinct perception about health and illness. Effective treatment plans for children with ASD requires tailoring interventions to the specific needs of each individual, and exuding sensitivity towards cultural beliefs and values, and traditional health beliefs and perceptions.

The unique historical context of Filipino Americans may also influence parental interaction with health care providers. Cultural values were heavily influenced by periods of American and Spanish colonization—roughly 50 years and 370 years, respectively (Nadal, 2011). Unlike other Asian ethnic groups, Filipinos are the only group to incorporate emotionally expressive communication patterns and display warmth in their interpersonal interactions (Nadal, 2011). East Asians embrace a different communication style—one grounded in reason and logic, and free from emotional expression (Nadal, 2011). Moreover, interactions with health care providers are influenced by interpersonal traits. Filipinos' perception of health care providers can be described as one of two types: (1) *hindi ibang tao,* or "one of us"; or (2) *ibang tao,* or "not one of us" (Sanchez & Gaw, 2007, p. 813). Those who are viewed as *hindi ibang tao* exude a combination of courteous, welcoming, and eager to help, and can be trusted by the Filipino patient and family (Sanchez & Gaw, 2007). Health care providers considered *ibang tao* are not trusted, thus Filipinos may be reserved in disclosing their concerns and feelings about their health issues and problems (Sanchez & Gaw, 2007).

Statement of Purpose

The purpose of this research study is to explore the beliefs and perceptions surrounding ASD in the Filipino American culture and to describe how Filipino American parents manage care for children and adults with ASD. Cultural beliefs and values influence how individuals perceive health, illness, and disability. Garnering knowledge from a cultural perspective provides insight into means to improve health care quality and access through integration of culturally sensitive care.

Research Questions

The primary research questions to be addressed in this research project are: (1) What are Filipino American cultural beliefs and perceptions about ASD? and (2) What are the experiences of Filipino American parents managing care for children and adults with ASD?

Specific Aims

The study's specific aims are: (1) to explore Filipino American cultural beliefs and perceptions about ASD; (2) to describe how Filipino American parents manage care for children and adults with ASD; and (3) to generate an explanatory framework on processes involved in Filipino American parental management of care for children and adults with ASD.

Significance

Research efforts exploring ASD in the context of Filipino American culture is essential to the advancement of nursing science and the practice of cultural competent nursing care. Moreover, this impacts health and education outcomes for both the individual with ASD and their families. Understanding cultural beliefs and perceptions about ASD in the Filipino American community is crucial for identifying barriers to help-seeking behavior and subsequent treatment of ASD. Minority populations have unique health care needs that may stem from traditional health beliefs, perceptions, and practices, as well as traditional cultural values. Capturing and addressing these unique health care needs requires expanding the scope of research efforts to garner knowledge on ASD in a cultural framework.

Shame and stigma associated with ASD hinders Filipino Americans from seeking health care to alleviate symptoms, promote independence, and optimize health. Families cope with the chronic nature of the disability on various levels—grieving the "loss" of the normal child and managing the special needs of the child. Parents may even experience stressors associated with caregiving, which can affect their overall health status and subsequently influence different spheres of their life, such as work, school, finances, and relationships. Parenting a child with autism has been associated with high levels of parenting stress due to the complexity of managing the child's condition (Phetrasuwan & Miles, 2009). Due to the challenges associated with impairment on multiple levels, parents also experience various concerns, such as worrying about their child's future and experiencing stigma from others (Phetrasuwan & Miles, 2009). Gaining insight about ASD in the context of parenting within a Filipino American family is salient for providing culturally appropriate care to manage this developmental disability.

Nursing Implications

Research studies focusing on Filipino Americans and ASD will contribute to the knowledge base of cultural competency in nursing care. Study findings will provide the groundwork for establishing culturally sensitive protocol in screening, diagnosing, and managing ASD in Filipino Americans. Development of validated screening tools for Filipino Americans would assist with early identification of the developmental disability. Implementation of culturally tailored programs that incorporate cultural beliefs and values and integrate traditional treatments and practices would help Filipino American parents manage their child's ASD on a daily basis. Moreover, promotion of autism awareness campaigns is vital for educating the Filipino American community about the developmental disability. Such campaigns will improve visibility of ASD, reduce stigma linked with the developmental disability, and garner social support for Filipino American parents raising a child with ASD. Gaining insight about ASD in the context of parenting within a Filipino American family is salient for health care providers to ensure a sound understanding of how the developmental disability affects the family unit, and minimize negative health consequences for the individual with ASD.

Summary

This first chapter presents an overview of the research study as well as the state of the science regarding Filipino American beliefs and perceptions about their experience managing care for children and adults with ASD. The significance of the study, background information on ASD, as well as the implications for nursing science is presented. Chapter Two introduces the theoretical framework, social constructionism, which guides the study. The chapter also discusses philosophical underpinnings, symbolic interactionism and pragmatism, that influence the methods. Chapter Three provides a literature review covering the beliefs and perceptions regarding managing care for a child with ASD, supplemented by a review of traditional Filipino beliefs, perceptions, and practices. The chapter synthesizes findings from studies related to ASD, management of care, and Filipino Americans. Chapter Four provides a detailed description of the research methods employed to conduct the qualitative research study using grounded theory. The chapter emphasizes the methods and processes employed to ensure that the qualitative research approaches address the research questions while upholding ethical standards to protect research participants. Chapter Five outlines the findings from the research study. The chapter addresses each of the specific aims. Chapter Six is comprised of a discussion of the major study findings. The chapter utilizes the research findings to set forth implications for nursing research and practice.

CHAPTER TWO

THEORETICAL FRAMEWORK

Theoretical Perspective

Symbolic interactionism and social constructionism are two theoretical perspectives that guide this research study. These perspectives, rooted in sociology, are the frameworks for which data was collected and analyzed.

Symbolic Interactionism

Symbolic interactionism emphasizes that individuals understand other individuals based on interaction—interaction with others and interaction with themselves—as opposed to using societal views or personality traits to glean understanding (Charon, 2010). An emphasis is placed upon the individual—or self—as an active person within the environment who engages in thinking while navigating and processing situations, as opposed to a passive person whose decisions and actions are shaped by existing norms and values (Charon, 2010). According to Charmaz (2014), symbolic interactionism encompasses human action as a means to develop one's self, define one's situation, and create society. An ongoing cycle exists where an individual may act upon a situation depending on their interpretation of the situation, and in turn, an individual may interpret a situation based on human actions—their own action or others' actions—related to the situation (Charmaz, 2014).

Historical Underpinnings of Symbolic Interactionism

Pragmatism heavily influenced the symbolic interactionism perspective. Pragmatism, based on the works of University of Chicago sociologist George Herbert Mead (1863-1931), views notions of usefulness or practicality as central for gaining knowledge and understanding truth (Charon, 2010). Knowledge is attained through how well an individual perceives information as useful in situations they encounter (Charon, 2010). Individuals actively view knowledge and truth based on the degree of applicability to navigating situations and interactions in their life (Charon, 2010).

Premises of pragmatism. Pragmatists hold four ideas central to their school of thought (Charon, 2010). The first premise states that human beings actively interpret what is going on in the environment in which they partake (Charon, 2010). For instance, if an individual sees a duck, an individual may perceive this duck in different constructs. One individual may see the duck as a potential pet, yet another person may see this duck as an animal that can lay eggs. An individual is engaged in an "interpretive process" that influences what an individual deems as knowledge or truth (Charon, 2010, p. 30).

The second premise of pragmatism describes the degree of usefulness as central to what a human being describes as knowledge or truth (Charon, 2010). Information may be presented to an individual though various avenues, such as through work or school, but an individual may deem this information as true knowledge if a high degree of applicability to life situations exists (Charon, 2010). For example, if a nursing student was told by experienced nurses that he or she would be guaranteed to pass their nursing licensure exam only by completing practice questions, and this nursing student heeds this advice, takes the exam, and does not pass, the nursing student would infer that practice questions do not lead nursing students to pass their licensure exam, and come to the conclusion that the information is false knowledge, or untrue. Individuals apply practicality to discern truth and knowledge from falsehoods in situations or environments in which they are placed (Charon, 2010).

The third premise of pragmatism encompasses that human beings employ selectivity in noticing objects that are rendered practical or useful in various situations or environments to attain a goal (Charon, 2010). For instance, nurses may deem a stethoscope in a clinical setting as useful in practice, as a way to assess the human body. Stethoscopes can be used for listening to a myriad of sounds, such as lung sounds, heart sounds, and bowel sounds, to determine if a bodily system is functioning normally. Although some nurses may note other tools in the environment that they are in, such as lights in the exam room, the stethoscope is the tool that would assist the nurse in the goal of completing a nursing assessment. Charon (2010) notes that objects are present in situations and environments, but individuals are drawn to objects that are relevant to achieving their goal.

Last, the fourth premise of pragmatism emphasizes the role of human beings as actors (Charon, 2010). Human beings are not merely viewed as passive persons who are characterized by personality or traits, but rather as active players in situations (Charon, 2010). For example, one may characterize a pediatric medical-surgical nurse as an individual who works with patients from infancy to adolescents who have medical conditions, such as pneumonia, or who are undergoing surgical procedures, such as an appendectomy (removal of the appendix). A pragmatist would view this pediatric medical-surgical nurse from a different perspective—one who provides the patient with pneumonia with care to alleviate their symptoms, such as raising their head of bed to facilitate breathing or administers morphine for the patient after their appendectomy to alleviate their pain. From the pragmatist point of view, human beings are best understood through gleaning insight into actions taken in a situation—reflecting upon why an individual selected a specific course of action and how this course of action positively or negatively influences other individuals or situations, as well as how an individual views or perceives their own actions and others’ actions (Charon, 2010).

Premises of symbolic interactionism. The sociological perspective of symbolic interactionism was originally conceived by Herbert Blumer (1900-1987), a sociologist who studied under the auspices of Mead at the University of Chicago (Blumer, 1969; Charmaz, 2014). Blumer (1969) devised three premises of symbolic interactionism that emphasizes the salience of meaning to human beings. The first premise states that "human beings act toward things on the basis of the meanings that things have for them" (Blumer, 1969, p. 2). This premise clarifies that "things"(p. 2) encompass much more than objects (e.g., table), but also include other individuals (e.g., teacher), groups of individuals (e.g., classmates), social institutions (e.g., religion), guiding principles (e.g., respect), interactions with other individuals (e.g., taking an order from a supervisor), and situations or events (e.g., getting a physical exam) (Blumer, 1969). For example, an individual running a 5K (3.1 mile) race observes volunteers handing out cups of water at the 1-mile mark. Based on prior races, this person immediately takes the cup of water to drink in order to prevent dehydration, as water is a symbol for hydration.

The second premise states that "the meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows" (Blumer, 1969, p. 2). This premise suggests that meanings are socially constructed through interacting with other individuals. For instance, the 5K runner may have learned to drink water for hydration from members of his or her running group or observed other runners drinking water at the 1-mile mark in a previous race. Through interacting with other individuals, one learns norms and values in a given social group or social situation.

Lastly, the third premise states that "these meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he encounters"

(Blumer, 1969, p. 2). This premise notes that meanings are subject to change based on the individual's interpretation of the thing through various situation or event. For instance, the 5K runner arrives at the 2-mile mark and starts to pick up the cup of water to drink. Then, he or she notices another runner taking a cup of water and pours the water on top of his head. The runner quickly asks the other runner why he or she poured the water on top of their head. The other runner then replies back saying that he or she was warm and sweating profusely and needed the water to cool down. The 5K runner continues to run the race and starts feeling warm and sweats profusely upon approaching the 3-mile mark. Upon seeing the cups of water, he or she decides to pour the water on top of their head to cool down and immediately feels more refreshed and cooler. Based on this action, the runner has a new meaning for water—an object that hydrates the body and keeps the body cool. Meanings are subject to transformation in the context of interpretation of social interactions and encounters.

Major Concepts in Symbolic Interactionism

Symbol. Symbols exist as an integral component to symbolic interactionism. According to Charon (2010), symbols are social objects, which are objects that are either physical objects (e.g., chair) or abstract objects (e.g., value) that are deemed useful to a human being in a situation and are created through social interaction. Charon (2010) characterizes three types of symbols used in human interaction: (1) objects (e.g., color, such as blue to signify sadness); (2) words (e.g., language as form of communication); and (3) acts (e.g., opening door to signify chivalry) (Charon, 2010). Symbols serve various purposes in social interaction, such as purposeful communication with others and meaningful expression about thoughts and ideas (Charon, 2010).

Symbols also serve as significant forces in three aspects of the human experience—social life, social reality, and the individual (Charon 2010). Regarding social life, symbols are tools that are used in different components in everyday life, including cooperating with others to attain a personal or collective goal, communicating with others to express thoughts or take action, establishing and maintaining a shared culture, socializing an individual into a social group, and archiving knowledge (Charon, 2010). In social reality, individuals do not perceive reality by merely accepting what exists, but rather utilize symbols as a means to understand and interpret situations that individuals are placed in (Charon, 2010).

Lastly, individuals use symbols through nine distinct tasks: (1) perceiving the world; (2) thinking about one's reality; (3) transcending time and space to reflect upon the past, present, and future; (4) seeing the world from another person's perspective; (5) problem solving and deliberating about potential actions; (6) fostering active, rather than passive, behavior; (7) being able to envision abstract, rather than lived, reality, such as an afterlife; (8) using language to identify and categorize objects and form memories; and (9) employing a sense of self-direction to address situations that one may face (Charon, 2010).

Self. The notion of self is central to the symbolic interactionist perspective. According to Charon (2010), self is defined as "an object of the actor's own action" (p. 71). Therefore, there is a duality of self—a self that can act towards other individuals and a self that can act towards oneself (Charon, 2010). Like symbols, self is viewed as a social object because it is rooted in social interaction, where a person becomes an object from the perspective of others (Charon, 2010). A two-way process emerges, where other individuals may label or categorize the self (e.g., you are a pediatric nurse), and in return, the self internalizes this information (e.g., I am a pediatric nurse) (Charon, 2010).

Development of self. The development of self occurs over four distinct stages (Charon, 2010). First, the preparatory stage involves a young child using imitation as a means for social interaction, where such actions are not given meaning (Charon, 2010; Mead & Morris, 1934). For instance, a mother may give a stuffed animal a hug, and the child would also give a stuffed animal a hug. The action of hugging the stuffed animal is not symbolic or understood by the child. Second, the play stage incorporates meaningful social interaction with another individual, as language skills are acquired and children can assume the role of the other (Charon, 2010; Mead & Morris, 1934). For example, two toddlers may decide to play "house," and one child may pretend to be the father and the other child may pretend to be the son. The roles that children assume in this stage are those of "significant others," individuals who may be deemed as influential or important to the child (e.g., parent, teacher, coach, etc.) (Charon, 2010; Mead & Morris, 1934, p. 74). The social interaction occurring during play is simplistic in the sense that children define their own rules of play amongst themselves and able to undertake the role of only one significant other at a given point (Charon, 2010; Mead & Morris, 1934).

Third, the game stage commences when an individual considers the viewpoint of multiple individuals (Charon, 2010; Mead & Morris, 1934). This stage emerges later in childhood, where the child undertakes the role of the "generalized other," a group comprised of significant others (Charon, 2010; Mead & Morris, 1934, p. 75). For instance, a child may play on a soccer team and undertake the perspectives and roles of all the other members in their team to play a successful game. This stage requires a higher complexity of understanding, as the child uses the "generalized other" to integrate into society through learning about societal rules and norms (Charon, 2010). Last, the reference group stage exists as a social reality in which the individual simultaneously partakes in several societies or social groups (Charon, 2010; Shibutani, 1955).

For example, a doctoral student in nursing may have multiple reference groups, such as their cohort of classmates, their coworkers in the clinic, their family, and their friends. The development of self as a whole integrates perspectives from all the reference groups, and management of social interaction with a certain reference group uses the established rules and norms of the group (Charon, 2010; Shibutani, 1955).

Another aspect of self includes taking action towards oneself in different situations (Charon, 2010). Three actions of self include: (1) self-perception; (2) self-control; and (3) self-communication. First, self-perception requires an individual to view themselves while he or she is in a situation (Charon, 2010). Through self-perception, a person can reflect upon their actions during social interaction. There are three components of self-perception, which include self-judgment, where a person critically evaluates oneself, self-concept, where a person establishes their sense of self from a culmination of emotions and thoughts about oneself, and identity, where a person labels oneself through a name that embodies personal attributions in social contexts (Charon, 2010). An individual's identity can range from static to dynamic in nature—"basic" identity does not change (e.g., age); " general" identity characterizes an individual into a reference group (e.g., nurse); and "independent" identity is fluid and situational (e.g., mayor) (Charon, 2010, pp. 85-86)

Presentation of self. Erving Goffman (1922-1982) was a sociologist whose work primarily focused on the "interaction order," which placed an emphasis on various elements of social interaction, including processes, structures, and products (Charon, 2010). Goffman's most notable work, *The Presentation of Self in Everyday Life,* focuses on the concept of dramaturgy to describe social interaction through the lens of drama via a theatrical setting (Charon, 2010; Goffman, 1959; Wallace & Wolf, 1999). In this perspective, social life is perceived through the metaphor of “staged drama,” where actors perform on a stage (Charon, 2010, p. 169). There are various elements of this staged drama that provide context for social interaction: interaction, performance, and impression management.

Interaction. Goffman (1959) provides two definitions for the term interaction: (1) “the reciprocal influence of individuals upon one another’s actions when in one another’s immediate physical presence” and (2) “all the interaction which occurs throughout any one occasion when a given set of individuals are in one another’s continuous presence” (p. 15). For example, interaction may occur when two students are discussing the best approach to solve a calculus problem, where one student may describe their approach to the problem while the other student processes and listens, and vice versa.

Performance. Goffman (1959) describes that a performance ensues when “all the activity of a given participant on a given occasion which serves to influence in any way any of the other participants” (p. 15). For instance, a performance may occur between a restaurant server and a customer deciding to purchase dessert after a large meal. The server may bring a tray of all the desserts offered by the restaurant to show the customer and discuss each dessert in-depth in hopes of influencing the customer to purchase one.

Impression management. Impression management occurs when an individual seeks to control and sustain the impression in which he or she places upon others through their actions and appearance (Goffman, 1959). Such management occurs through a two-way process in which one individual, the actor, attempts to express themselves to another individual or group, the audience, who, sequentially, will be “impressed” upon by the actor (Goffman, 1959, p. 2).

Sign activity. For an actor to express oneself, he or she would communicate through one of two forms of “sign activity”: (1) the expression that one “gives,” and (2) the expression that one “gives off” (Goffman, 1959, p. 2). The expression that an actor “gives” is one that involves verbal communication that is purposeful and controlled (Goffman, 1959, p. 2). For example, if an individual receives a birthday gift from a friend at their birthday party, the individual would verbally thank their friend to express gratitude. On the other hand, the expression that an actor “gives off” is one that involves non-verbal communication that is accidental and uncontrolled (Goffman, 1959, p. 2). For example, if an individual opens the birthday gift from their friend, dislikes it, but does not want to hurt their friend’s feelings, the individual may verbally thank their friend to express gratitude, but simultaneously frown, as he or she is unhappy with the gift.

Front stage. According to Goffman (1959), front stage refers to “that part of the individual’s performance which regularly functions in a general and fixed fashion to define the situation for those who observe the performance” (p. 22). Front stage sets the scene for the situation in which the actor performs. There are two types of front stage: (1) “scenic front” and (2) “personal front” (Goffman, 1959, pp. 22-24). Scenic front encompasses the environment in which the performance will take place (Goffman, 1959). This environment, known as “setting,” includes both “stage props”—objects that the actor will use in their performance to convey their role (e.g., a nurses’ stethoscope)—and “background items”—equipment used to set the scene (e.g., hospital bed and intravenous pole, pump, and fluids). Goffman (1959) also describes the duality of setting as both static and dynamic. A static setting exists when an actor’s performance occurs only when he or she is in a specific setting where a performance commences when actor enters setting and performance concludes when actor exits setting (e.g., hospital room or classroom) (Goffman, 1959). A dynamic setting occurs when actors perform in a setting that moves with the actor (e.g., parade route or funeral procession) (Goffman, 1959).

Personal front includes an individual's characteristics (e.g., race, ethnicity, age, gender, etc.) or objects to express oneself (e.g., clothing, accessories, etc.) (Goffman, 1959). Two types of personal front exist: (1) "appearance" and (2) "manner" (Goffman, 1959, p. 24). Appearance embodies both "ritual state," a transient phase of an individual's life, such as partaking in work functions or social activities and experiencing life stages or historical times, as well as "social status," an individual's rank or position in relation to other members of society (Goffman, 1959, p. 24). On the other hand, manner encompasses the behavior that an individual gives off during the performance (Goffman, 1959). For example, a nurse may hug the grieving widow of a patient that passed away in the intensive care unit to portray compassion.

Backstage. Goffman (1959) describes "backstage" as "a place, relative to a given performance, where the impression fostered by the performance is knowingly contradicted as a matter of course" (p. 24). Contrary to front stage, where actors put on a performance that is rehearsed or may be covert in nature, backstage involves actors who are behind-the-scenes and are overt in presentation. For example, a restaurant server may enter front stage, where he or she serves a customer at a fancy restaurant who ordered a steak "medium rare." Upon the arrival of their steak, the customer complains the steak is still pink and should be brown, and accuses the server for taking the order incorrectly. The server calmly apologizes and takes the steak to the kitchen, or backstage, where the steak is cooked by the chef more thoroughly, and complains to his coworkers about the "demanding" customer.

A distinct delineation exists between front stage and backstage. There is often a physical partition, such as a curtain, door, or hallway that divides the two areas and allows the actor to seek assistance during their performance with others who are backstage (Goffman, 1959). The backstage area is candid, where the actor can come "out of character" whereas the front stage area is controlled, where the actor plays their character (Goffman, 1959, p. 113). For example, a novice nurse may prepare to administer an intravenous antibiotic to a patient with cellulitis (skin infection). Although the nurse has given this medication to a patient under the guidance of a nurse preceptor during residency, the nurse may have to review the process of preparing and administering the medication with a more experienced nurse in the medication room, the backstage, prior to administering the medication in the patient's room, or front stage. The backstage allows for actors to have a private venue away from the audience, and where secrets of the performance are kept, and the front stage gives actors a public sphere to perform for their audience in character (Goffman, 1959).

Outside. Goffman (1959) describes "outside region" (p. 135) as the area that does not encompass the front stage and backstage regions. The outside is a space in which the performance is not taking place, and outsiders are individuals who do not partake in the performance (Goffman, 1959). For example, the lobby of a theater may be considered an outside region, where the performers in a musical can meet audience members outside the context of the show. In this situation, the performers are not in character and can socialize with the audience without having to manage a character.

Looking-glass self. Charles Horton Cooley (1864-1929) was an American sociologist who coined the "looking-glass self," which describes that one's notion of self is derived from reflecting upon opinions that others have placed on oneself through social interaction (Wallace & Wolf, 1999, p. 195). The concept of looking-glass self, introduced in *Human Nature and the Social Order,* is comprised of three components (Cooley, 1902). The first component states, "the imagination of our appearance to the other person" (Cooley, 1902, p. 184). For example, a high school student spends numerous hours writing a book report on Jane Austen's *Emma*, and sees herself as an excellent, hard-working student. The second component states, "the imagination of his judgment of that appearance" (Cooley, 1902, p. 184). For instance, the student receives her book report back from her teacher with many corrections in red ink and earns a C on the assignment. Last, the third component states, "some sort of self-feeling, such as pride or mortification" (Cooley, 1902, p. 184). For example, the student views herself as an excellent or poor student.

Mind. Mead describes mind as the process of thinking that captures taking action towards oneself (Charon, 2010; Mead & Morris, 1934). Mind is distinct from taking action towards others because individuals in the environment are unable to tap into the inner thoughts on an individual (Charon, 2010). The hidden nature of mind consumes individuals while they are awake, as ongoing conversations with oneself commence (Charon, 2010). Through these conversations, a person engages in mind action, where he or she interprets situations and environments in which he or she are placed in, and uses the interpretation to determine how to take action or elicit useful information from the situation or environment (Charon, 2010). Mind action allows one to exert control over taking action in a situation, as internal dialogue with oneself helps a person methodically act, rather than make impulsive decisions in a situation as well as engage in solving problems through critical thinking and internal deliberation about situations at-large (Charon, 2010).

Action. Human action in social situations is fueled with both interaction with self and interaction with others (Charon, 2010). Individuals do not view reality as a sequence of distinct acts, but rather as a "stream of covert action," where there is constant, ongoing internal dialogue with oneself about encounters faced in daily life (Charon, 2010). From this dialogue, a person constantly thinks about and processes the situation as well as analyzes and evaluates social interaction, and in turn, makes decisions and takes action (Charon, 2010). In society, individuals engage in acts, which are overt actions, in social situations, such as baking a cake, writing a paper, or playing a song on the piano, to attain an overarching goal, such as bringing dessert to a potluck, fulfilling course requirements, or partaking in a concert, respectively (Charon, 2010).

Mead conceptualizes the notion of "act" into four distinct stages (Charon, 2010; Mead & Morris, 1934). The first stage, impulse, occurs when individual experiences a strong inclination to take action (Charon, 2010, Mead & Morris, 1934). Often, there may be impetus for a person to act, such as attaining a goal, overcoming a challenge, or solving a problem, and may result in the individual to feel unbalanced (Charon, 2010). For example, a nursing student is months away from graduation and realizes that he or she needs to apply for a nursing position. The second stage, perception, involves the process of identifying useful social objects in a situation to help the individual meet their goal, face their challenge, or address the problem (Charon, 2010). Individuals take a critical look of the situation that they are in to recognize social objects that will lead them closer to their goal (Charon, 2010). For instance, a nursing student may decide to speak to a nurse recruiter about job opportunities and resolve to purchase a test preparation book to help prepare for the nursing licensure exam.

The third stage of the act, manipulation, requires the individual to take action to reach their desired focus—reaching their goal, thriving over adversity, and resolving the problem (Charon, 2010). This stage requires social interaction, where the individual takes purposeful action to influence the environment to meet their needs (Charon, 2010). For example, a nursing student may schedule an appointment with the nurse recruiter and come prepared with a cover letter, resume, and "elevator speech" to convey strong interest in the hospital in which he or she would like to work, and may enroll in a test preparation class after graduation. The final stage of the act, consummation, is the point where the individual reaches their goal, overcomes their challenge, or solves their problem (Charon, 2010). This stage leaves the individual regaining a sense of balance in their life until another disruption of balance may occur from internalizing their social interactions (Charon, 2010). For instance, shortly after graduation, the individual lands a job at their dream hospital and passes their nursing licensure exam during their first attempt. There are several influencing forces that nudge an individual to take a course of action: (1) social institutions or influences (e.g., profession, culture); (2) individual personality (e.g., academically ambitious); (3) free choice (e.g., free will); (4) emotion (e.g., anger); (5) motives (e.g., extrinsic reasons); or (6) past experiences (e.g., becoming a public health nurse after providing health education and preventative screenings in disadvantaged areas) (Charon, 2010).

Taking the role of the other. Taking the role of the other is an element of symbolic interactionism that involves perceiving reality from the viewpoint of another individual or collective group (Charon, 2010). According to Mead, there are two types of "other"—"significant other" and "generalized other" (Charon, 2010; Mead & Morris, 1934). A significant other is an individual who one perceives to be important, including persons that an individual personally knows (e.g., family, friends, acquaintances) or a public figure (e.g., politician, activist, celebrity) whereas a generalized other is comprised of the collective beliefs and attitudes of a social group or community (e.g., Roman Catholics, Americans) (Charon, 2010; Mead & Morris, 1934). The process of taking the role of the other requires imagination, as one uses their mind to develop a representation of how other persons may view their world (Charon, 2010). Individuals learn how to interact with others through this process, as they can reflect upon another perspective to make decisions or take action and can gain insight into feelings and emotions.

For example, an individual has a best friend who lived alone and was very sick with the flu, unable to drive and purchase food, beverages, and medication. This individual imagines how it would be like having the flu—experiencing a high fever, muscle aches, sore throat, headache, and stuffy nose—and what he or she would like if they were sick—medications to relieve symptoms, such as acetaminophen for fever, an analgesic or cough drops for the sore throat, and a decongestant for the stuffy nose, as well as non-pharmacological items for symptom relief, such as a cool wash cloth to reduce body temperature, hot tea with lemon and honey for the sore throat, and chicken noodle soup for the congestion. Moreover, the individual may imagine emotions their best friend may have, such as feeling upset, sad, worried, or anxious about being sick and unable to work. Through visualizing what their best friend may be experiencing, it influences the individual to take action to visit their best friend, provide emotional support, and bring items to help alleviate physical symptoms associated with the flu.

Taking the role of the other has implications for both the self and society. Regarding the self, a maturation process occurs when an individual places him or herself in the perspective of others (Charon, 2010). An individual is able to utilize critical thinking in their development of self through various processes, such as the ability to reflect upon oneself, to make decisions, to take action, to take leadership, and to analyze oneself (Charon, 2010). Regarding society, an individual is able to exert social control through understanding multiple perspectives and taking action through consideration of these perspectives (Charon, 2010). Through taking the role of the other, social norms are upheld and maintained, and societal groups are able to function effectively through understanding the role each person has in their group (e.g., baseball team comprised of various positions that work together to play the sport) (Charon, 2010). Moreover, taking the role of the other allows individuals to engage in a complex and continuous learning process where various beliefs and perspectives are understood, as well as utilize critical thinking while taking action in different situations, as failure to consider the role of the other may lead to harmful or detrimental consequences (Charon, 2010).

Social interaction. Social interaction is a process that emerges when an individual communicates with others through symbols, acknowledges other persons present in the situation, and yields understanding of others' actions (Charon, 2010). This process utilizes taking the role of the other, as human actions are dependent on the interpretation of actions that others take in a situation (Charon, 2010). For instance, a game of tic-tac-toe illustrates social interaction. Each player, symbolized by taking on the "X" or "O" game pieces, shares a common goal of getting three "X's" or three "O's" in a row, column, or diagonally first in a three-by-three grid to win the game. Once the first player places their letter into the game board, the second player strategically places their letter onto the board based on the placement of the first player to prevent the first player from winning while simultaneously finding a path for themselves to potentially win the game.

Charon (2010) illustrates four functions of social interaction: (1) cultivation of "basic human qualities" (p. 140) through communicating using symbols, understanding reality through perspectives, perceiving the self and the mind, and engaging in processes, such as taking the role of the other and making decisions; (2) course of action in a situation results from social interaction, where interpretation of interaction between individuals affects how decisions are made and actions are taken; (3) establishment of identities through a process of presenting oneself to be a certain type of person to others, interpreting others as a certain type of person, and simultaneously internalizing what others say about oneself; and (4) development of society through sustained interaction amongst individuals over the course of time.

Society. From the symbolic interactionist perspective, society can be defined as interactions between persons that influence how an individual acts (Charon, 2010). Society can be viewed as a process that is dynamic in nature, where the notion of progress or change that occurs through social interaction is central to how societies develop over time, as opposed to a static state, where societies influence individuals through socialization processes embedded within social institutions and stratification and cultural values and patterns (Charon, 2010). Societies are comprised of three qualities: (1) symbolic interactionism, (2) cooperative action, and (3) culture.

Symbolic interactionism. Symbolic interaction between individuals occurs as an interdependent process, where individuals take each other's actions into consideration when taking their own action (Charon, 2010). A back-and-forth process occurs, where each person's actions is internalized to determine their next course of action in a situation. Through a communicative process, symbols used between individuals are used to understand and interpret the situation in which they are part of, which consequently sustains societies (Charon, 2010).

Cooperative action. Cooperative action exists as a process where cooperation amongst individuals is inherent to maintain societies (Charon, 2010). This process requires a willingness for all members of a society whose members may uphold a diverse set of beliefs, values, perspectives, and opinions, to work together and compromise in a given situation (Charon, 2010). Through cooperation, personal goals and interests are set aside for the collective whole, or society.

Five elements are salient for cooperative action: (1) "ongoing communication" as a continuous stream of verbal and non-verbal communication where all individuals are available to address the current situation; (2) "mutual role taking" as a conscious effort to recognize and internalize others' actions; (3) "defining others as social objects" as recognition that individuals hold a social identity (e.g., pediatric nurse) that simultaneously influences their own personal goals as well as positively contributes to societal goals; (4) "defining social objects together" where individuals have a common interest requiring attention (e.g., planning a fundraiser to support pediatric cancer patients); and (5) "developing goals in interaction" where individuals develop mutual goals to attain (e.g., raising $20,000 for pediatric cancer patients) (Charon, 2010, pp. 155-156).

Culture. Culture is a shared set of beliefs, values, goals, language, attitudes, and norms that emerge from a society (Charon, 2010). Individuals within a society view their world from a cultural perspective, where their actions may be influenced by culture (Charon, 2010). As a "shared perspective," understanding culture nurtures communication with others and subsequently fosters cooperation with others (Charon, 2010, p. 158). Last, culture serves as a "generalized other," where an individual's actions and behavior are guided by customs, values, traditions, taboos, rules, and procedures (Charon, 2010, p. 158). Members of society exert a sense of self-control through their interaction and communication with others to establish smooth relationships within society and avoid stressful situations involving impulsive actions and unwarranted behavior (Charon, 2010).

Symbolic Interactionism and Filipino American Parental Beliefs and Perceptions of ASD

Symbolic interactionism and pragmatism are salient to Filipino American parental beliefs and perceptions of ASD because interactions with self and others and usefulness of tools and information may influence the care and treatment a child or adult with ASD receives. Mothers and fathers process their social interactions with others in their day-to-day care of the developmentally disabled child or adult. They actively reflect upon conversations they have had with others, such as other parents, teachers, friends, family, and health care providers, to help navigate the daily and long-term challenges the individual may face. Based on these interactions, parents are able to gain knowledge about ASD and take action to manage the developmental disability across the lifespan through discerning information that is pertinent and useful to their unique situation. Addressing illness and disability across cultures requires recognition of beliefs and values that are important to an individual, and may be gleaned through understanding the social context in which individuals live as well as personal interactions that influence how individuals act in their daily lives.

Social Constructionism

Social constructionism is a perspective that employs that an individual forms their "social reality(ies)" based on their actions with others and themselves (Charmaz, 2006, p. 189). Such interactions are used to construct and frame reality (Gergen, 2009). Social constructionism is salient for developing meaning and drawing significance on life events. Moreover, this theoretical perspective utilizes actions as a tool for constructing experiences, positions, and perspectives of people (Charmaz, 2006).

Assumptions of Social Constructionism

According to Gergen (2015), social construction is contingent upon an individual's worldview based on the social relationships in which one partakes. Gergen (2015) outlines four assumptions of this theoretical perspective. The first assumption states, "the ways in which we describe and explain the world are not required by 'what there is.'" (Gergen, 2015, p. 7). This assumption describes that reality for one individual may differ from reality as seen from another person. For example, a fish may be seen as food from the reality of one person, but this same fish may be perceived as a pet from the reality of another person. There is not one correct definition of fish; rather there are multiple definitions of fish that exist. The second assumption states, “the ways in which we describe and explain the world are the outcomes of relationship” (Gergen, 2015, p. 8). Social relationships foster how the world is viewed and understood. For instance, a child may learn that a lemon is yellow, not simply on their own, but rather from their teacher, who teaches the child and his or her classmates that the lemon is the color yellow.

The third assumption states, “constructions gain their significance from their social utility” (Gergen, 2015, pp. 9-10). This assumption demonstrates the concept of social utility, where constructs are valued based on the degree of usefulness to the group (Gergen, 2015). Beliefs and values that are salient in a social group are noted in their communication patterns, such as language, material objects, such as tools, and environmental settings, such as location (Gergen, 2015). For instance, Gergen (2015) described the construct of a tennis game through jargon specific to tennis, such as “thirty love” or “serve” (p. 10), tools to play tennis, such as rackets and a ball, and a venue to play tennis, such as a court. Such aspects are salient and useful to a social group—tennis players. The fourth assumption states, “values are created and sustained within forms of life—including science” (Gergen, 2015, p. 11). This assumption describes that values and norms in society are derived from language, human relationships, and “patterns of living” (Gergen, 2015, p. 11). For instance, if a driver ran a red light, other drivers may honk their horn to communicate that they are breaking norms and laws pertaining to driving a vehicle, as it is universally understood by drivers that red indicates stop, yellow indicates yield, and green indicates go.

Major Concepts in Social Constructionism

Standpoint. Standpoint is a frame of reference is which an individual constructs reality and views their world (Gergen, 2015). Each individual holds a distinctive standpoint, as their personal interactions with others coupled with their life experiences shape their worldview. For example, the concept of death may be viewed differently through various perspectives—a physicist may perceive death as a transformation of atomic composition, whereas a biologist may comprehend death as cessation of bodily function (Gergen, 2015). Social institutions influence the way human beings understand, interpret, and perceive the world.

Language. Language is a communication tool that forms social institutions and nurtures interpersonal relationships (Gergen, 2015). Through vocabulary, social institutions are established and interpersonal relationships are maintained by utilizing shared meanings of words to convey thoughts, express opinions, communicate ideas, and discuss beliefs (Gergen, 2015). For instance, in the practice of nursing, various terms, such as "assessment" or "intervention," are necessary to care for patients in the social institution of nursing, where provider-patient relationships are sustained to promote health and well-being. Common vocabulary allows for social institutions to not only uphold culture and tradition, but also embrace perceived reality in an evolving world.

Reality. Relationships are comprised of social interactions that shape reality (Gergen, 2009). The notions of truth and reality are stemmed from relationships, specifically "through coordinations among persons—negotiations, agreements, comparing views, and so on" (Gergen, 2009, p. 6). As a result, there are multiple truths and realities in the world because various factors—social, cultural, political, economic, and historical—influence individuals' perspectives.

Critical reflexivity. Critical reflexivity is a process in which personal beliefs are questioned, multiple viewpoints are considered, diverse perspectives are acknowledged, and existing assumptions are analyzed (Gergen, 2009). This process is important in social constructionism, as grasping social patterns requires a critical view of reality through simultaneously letting go of upheld assumptions and leaving one's comfort zone, and bringing in multiple viewpoints and understanding unique personal experiences.

Social Constructionism and Filipino American Parental Beliefs and Perceptions of ASD

Traditional Filipino American health beliefs and perceptions may influence how parents view ASD. As a collectivist culture, Filipino Americans value social relationships and reality can be perceived through interactions with others. These social relationships form their lives and how they navigate dealing with the disorder. Managing ASD requires knowledge of important aspects involved with care for the child. Some tools that may be helpful to navigate ASD include pharmacological treatments (e.g., medication) or nonpharmacological treatment (e.g., vitamins). Terminology used in ASD includes terms that signify how individuals care for this developmental disorder, such as Individualized Education Programs (IEP), that conveys a degree of social utility. Social settings may include school or therapy sessions.

Standpoint is essential to understanding how Filipino American parents manage care for a child or an adult with ASD. Management of care for a child or an adult with ASD may be viewed differently from various standpoints, as a health care provider, such as a nurse practitioner, may furnish medications to help alleviate symptoms that the individual may have. A parent may incorporate daily routines to care for their child at home. Also, standpoints may take on various layers, such as gender and ethnicity, which influence how a child or adult is cared for as well as perception of the development disability.

Language—whether it includes English, Filipino/Tagalog, other Filipino dialects, or health or medical terminology—is crucial to fully understand how ASD is understood and managed by Filipino American parents. Some of the terms may include the etiology or trajectory of the disorder, as well as signs and symptoms of the disorder. Moreover, these terms may be health, medicine, social, or behavioral in context. Such words form the basis of communication amongst caregivers and health care providers.

Reality is essential to understanding how Filipino American parents perceive their experiences caring for a child or an adult with ASD. Individuals with ASD have complex symptoms that affect communication skills, social skills, and behavior. Day-to-day management of the individual may involve parents having relationships with various persons in their lives, such as family and friends, professional lives, such as coworkers and managers, as well as support systems, such as health care providers and educators. These relationships help navigate the parents' lived reality.

Cultural reflexivity is important for researchers due to their own personal beliefs and perceptions that may influence how data is interpreted. Investigating the cultural components that affect how Filipino Americans manage ASD is important, as perspectives on the developmental disability may be laden with cultural beliefs and perceptions that may differ from the mainstream population. Gathering knowledge about this population requires that individuals are knowledgeable about the cultural constructs of the illness, remain open-minded, and free themselves from underlying biases.

Summary

As philosophical underpinnings, symbolic interactionism and social constructionism are salient perspectives in understanding how Filipino American parents manage care for a child or an adult with ASD. Symbolic interactionism, which takes a microperspective, focuses on interactions between self and others to define one's situation in society. Social constructionism, which takes a macroperspective, considers socially constructed norms and values to interpret one's lived reality. Both perspectives allow an individual to construct their world.

CHAPTER THREE

LITERATURE REVIEW

Autism Spectrum Disorder

Prevalence of Autism Spectrum Disorder

Autism spectrum disorder (ASD) is found in all sociocultural groups in the United States (Centers for Disease Control and Prevention [CDC], 2020b; CDC, 2020e). Assessing the prevalence of ASD over time, however, has been difficult due to the intricacies of the disability (CDC, 2020b). Clinical diagnostic criteria evolved over the past decade and specific diagnostic biological markers have not been identified (CDC, 2020b). Additionally, data collected has been state-based, and can pose challenges in capturing the overall prevalence of the disability in the United States due to inconsistency. However, short-term prevalence monitored in the United States has proceeded through different means, such as the Autism and Developmental Disabilities Monitoring (ADDM) Network and the National Survey of Children's Health (NSCH) (Blumberg et al., 2013; CDC, 2020b).

Under the auspices of the CDC, the ADDM Network has gauged the prevalence of ASD based on data collected from various institutional sites since 2000 (CDC, 2020b). Most recently, 11 sites have monitored the surveillance of ASD and other developmental disabilities through collecting data from various states: Arizona, Arkansas, Colorado, Georgia, Maryland, Missouri, New Jersey, North Carolina, South Carolina, Utah, and Wisconsin (CDC, 2020b). Site selection entailed a rigorous review process, as each participating site needed to have the capacity to maintain accurate records of ASD surveillance and to cover a race/ethnicity diverse population of children (CDC, 2020b). Due to this process, the CDC emphasizes that this sample is not representative of the entire nation (CDC, 2020b), as the data collected targeted 8-year-old children who lived within the proximity of one of the 11 sites (CDC, 2020b).

According to the ADDM Network, approximately 1 in 54 children who are eight years of age are afflicted with ASD (CDC, 2020b). The prevalence of ASD is 29.7 per 1,000 children in boys and 6.9 per 1,000 in girls, where ASD is found to be 4.3 times more likely in boys than girls (CDC, 2020a; CDC, 2020b). Across racial/ethnic groups, non-Hispanic whites report a higher prevalence of ASD—18.5 per 1,000 children—compared to both non-Hispanic blacks and Hispanics—18.3 per 1,000 children and 15.4 per 1,000 children, respectively (CDC, 2020b). Approximately 17.9 per 1,000 children in Asian/Pacific Islanders were afflicted with ASD (CDC, 2020b).

A collaborative effort between the National Center for Health Statistics of the CDC and the Maternal and Child Health Bureau of the Health Resources and Service Administration (HRSA) monitored prevalence changes in ASD (Blumberg et al., 2013). A telephone survey administered to random households with non-institutionalized children between ages 0 to 17 years was based on the NSCH (Blumberg et al., 2013; Child and Adolescent Health Measurement Initiative, 2012b). This survey gathered data regarding a child's physical and mental health status, health care access, as well as sociodemographic characteristics through interviewing the adult most knowledgeable about the child's health history (Child and Adolescent Health Measurement Initiative, 2012a; Child and Adolescent Health Measurement Initiative, 2012b). Findings reported a significant rise in prevalence of parent-reported children with ASD from 2007 to 2011-2012. This prevalence ranged from 1 in 86 children in 2007 to 1 in 50 children during 2011-2012 (Blumberg et al., 2013). Researchers attributed these increases to various factors, including improvement in clinical diagnosis, raised awareness about ASD, greater access to services, and increased availability of community-based special education (Blumberg et al., 2013).

Signs and Symptoms of Autism Spectrum Disorder

Signs and symptoms of ASD often manifest through behavior, communication patterns, and social interactions prior to the child turning 3 years of age (CDC, 2019c). Some children may exhibit symptoms during early infancy, whereas others may exhibit symptoms during late toddlerhood (CDC, 2019c). Other children may regress in their development, such as children who reach developmental milestones until 18 to 24 months of age, and then reach a plateau with no further development or a loss of attained skills (CDC, 2019c). According to the CDC (2019c), parental observation of signs and symptoms of ASD often occurs prior to the age of 2 years—approximately 33% to 50% of parents noted developmental challenges in their child by 12 months of age, and approximately 80% to 90% of parents observed such changes in their child by 24 months of age.

Behavioral signs and symptoms. Behavioral signs and symptoms of ASD are comprised of two types—repetitive motions and routine (CDC, 2019c). Repetitive motions involve recurrent movements, where an individual engages in recurrent self-movement or movement of objects (CDC, 2019c). Examples of such repetitive motions include flapping one's hands, swaying one's body from side to side, or spinning oneself in circles, and recognized as "red flag" behavioral symptoms (CDC, 2019c). Placing an emphasis on routine is also central for individuals with ASD, as any deviation from an established routine (e.g., taking a different route home) or an atypical or uncommon routine (e.g., turning on all the lights at home after school) may cause behavioral outbursts such as tantrums or aggravation (CDC, 2019c).

Communication signs and symptoms. Communication patterns are unique to each individual with ASD (CDC, 2019c). Verbal communication ranges from little or no ability to express oneself verbally to exceptional speaking ability (CDC, 2019c). Less than half of all children diagnosed with ASD are non-verbal and approximately one-fourth to one-third of all children diagnosed with ASD lose ability to retain words by 12 to 18 months of age (CDC, 2019c). For verbal children with ASD, however, there may be an atypical use in language, such as echolalia, where the child displays repetition of words or phrases (CDC, 2019c). Interpretation of non-verbal communication, such as body language or gestures, may be challenging for the child with ASD who may misinterpret the meaning of such motions (CDC, 2019c). Other challenges in communication may include the inability to hold age-appropriate coherent conversations with others, as well as maintaining socially accepted personal space during conversations (CDC, 2019c).

Social signs and symptoms. Individuals with ASD face challenges during social interactions with others (CDC, 2019c). Such challenges cannot solely be attributed to personality characteristics, such as shyness, but rather social issues that permeate into the daily lives of these individuals (CDC, 2019c). Those with ASD may express social behaviors or reactions that seem incongruent to the situation in which they socialize (CDC, 2019c). For instance, a child with ASD may express a flat demeanor while others are laughing at a funny joke. Other individuals may view such incongruent social expressions negatively, which may lead to parental experience of stigma (Gray, 2002).

Social signs and symptoms may manifest at different developmental stages and may include disinterest in people and the external environment in infancy, disinterest in social games (e.g., playing pat-a-cake or peek-a-boo) in toddlerhood, and challenges with social interaction (e.g., cultivating friendships, expressing emotions) during childhood and beyond (CDC, 2019c). Additional signs of ASD include unusual sensory responses (e.g., overreaction to loud noise), dietary habits (e.g., consumption of specific foods, such as eating only macaroni and cheese), sleeping habits (e.g., refusal to sleep at bedtime), and emotional responses (e.g., expression of laughter when solemnity is expected) (CDC, 2019c).

Diagnosis of Autism Spectrum Disorder

Challenges exist in the diagnostic process for ASD as no specific tests exist to discern the presence of the developmental disability (CDC, 2020c). Rather, children are diagnosed with ASD through health care providers' development and behavioral observations of the child (CDC, 2020c). Both developmental screening and a comprehensive diagnostic evaluation are utilized to diagnose a child with ASD (CDC, 2020c). Diagnosis of ASD may occur as early as 18 months of age, but increased reliability of diagnosis often occurs by 2 years of age (CDC, 2020c). Later diagnoses often pose implications for children, as treatment of ASD is delayed (CDC, 2020c).

Developmental screenings encompass tests to determine if a child meets developmental milestones appropriate for their age (CDC, 2020c). These tests compare the child's development to a baseline expected for their age. Screenings occur at recommended intervals—9 months, 18 months, and 24 or 30 months—during well-child visits (CDC, 2020c). At 18 and 24 months, screenings for ASD are initiated at well-child visits (CDC, 2020c). As a ten-fold increased risk of ASD symptoms exists in younger siblings of those formally diagnosed with ASD, health care providers must screen with increased vigilance, as understated symptoms in infants may present (Johnson, Myers, & Council on Children with Disabilities, 2007).

Validated screening tools are categorized in two levels—level 1 and level 2—and may be used in children over 18 months of age, as no validated screening tools exist for use in younger children (Johnson et al., 2007). Screening tools categorized as level 1 distinguish normally developing children from those predisposed to ASD, and are generally administered in the primary health care setting (Johnson et al., 2007). On the other hand, screening tools categorized as level 2 distinguish children predisposed to ASD from those predisposed to developmental disorders other than ASD, and are administered in a specialty care setting, such as developmental or behavioral clinics, or early intervention programs (Johnson et al., 2007).

The diagnosis of ASD is not solely based on level 2 screening tools, but are comprised of a comprehensive evaluation (CDC, 2020c; Johnson et al., 2007). The comprehensive evaluation comprises of a rigorous assessment of the child's developmental and behavioral patterns based on parental or caregiver accounts and health care provider observations of the child (CDC, 2020c; CDC, 2020d). Additionally, results from various diagnostic tests are compiled to help formulate a diagnosis, such as diagnostic tools (e.g., Autism Diagnostic Observation Schedule—Generic; Autism Diagnosis Interview—Revised) or medical tests (e.g., genetic testing, hearing screening, neurologic testing, vision screening, etc.) (CDC, 2020c; CDC, 2020d).

Health care providers may diagnose ASD easily if the child meets standardized diagnostic criteria provided by the American Psychiatric Association's Diagnostic and Statistical Manual, Fifth Edition (DSM-5). Providers may face challenges, however, during the diagnostic process should the child manifest signs and symptoms that are mild or could be attributed to other disorders or disabilities (CDC, 2019a; Johnson et al., 2007). According to the DSM-5, an individual is considered to have ASD if he or she meets the following criteria:

(1) the individual presents with continuous deficits during social interaction and social communication;

(2) the individual exhibits at least two of the following behavioral patterns that are repetitive or restricted—focus on routine with little change; strong fixation on particular interests or objects; abnormal, repetitive bodily movements, and/or extreme degrees of reaction to sensory input found in their environment;

(3) the individual presents with symptoms during the early developmental stages of life;

(4) the individuals' symptoms impede social interaction and functioning; and

(5) the individuals' symptoms cannot be attributed to global developmental delay or intellectual disability (ID) (American Psychiatric Association, 2013; CDC, 2019a).

A team of health care providers and specialists often make the formal ASD diagnosis (Johnson, 2007). This team may comprise of specialty health care providers (e.g., developmental pediatrician, child neurologist, geneticist, child psychiatrist) and allied health care providers (e.g., early intervention specialist, pediatric speech therapist, pediatric occupational therapist, child psychologist, and pediatric social worker) (CDC, 2020c; Johnson et al., 2007). A diagnosis of ASD or a developmental disability warrants an urgent referral to an early intervention program, which is a government-sponsored program that provides services to children with developmental disabilities, such as individualized interventions and therapies, to address or alleviate symptoms associated with ASD or a developmental disability (Johnson et al., 2007).

In the pediatric setting, well-child visits provides parents or caregivers an opportunity to speak to a health care provider regarding their child's growth and development patterns, vaccination schedule, and issues pertaining to eating, learning, sleeping, socializing, and toilet training (American Academy of Pediatrics, 2014). These visits also provide the child with a physical examination and screening tests to identify potential growth and developmental problems, disease, or illness (American Academy of Pediatrics, 2014). On the other hand, sick visits are problem-based, where parents or caregivers bring the child to see a health care provider to address a specific health concern, such as respiratory symptoms (American Academy of Pediatrics, 2014). The well-child visit embraces a family-centered approach for medical care, as it incorporates a holistic perspective to promote health and well-being (American Academy of Pediatrics, 2014) and identifies the family unit as salient for fostering not only physical health, but also emotional, social, and developmental well-being for the child (Institute for Patient- and Family-Centered Care, 2010).

Treatment of Autism Spectrum Disorder

Treatment of ASD is comprised of a variety of modalities to help enhance daily functioning and ease symptoms (CDC, 2019d). Such modalities include: (1) behavior and communication programs and therapies; (2) complementary and alternative medicine; (3) dietary modifications or supplements; and (4) pharmacological treatments (CDC, 2019d).

Behavioral and communication programs and therapies. Behavioral and communication programs and therapies encompass approaches to encourage direction, organization, and structure into daily functioning, as well as promote integration into the family unit (CDC, 2019d). Through these programs and therapies, individuals with ASD learn to engage in positive behavior through applied behavioral analysis (ABA), as well as enhance emotional and relational skills and improve management of sensory input through floortime, or developmental, individual differences, relationship-based (DIR) approach (CDC, 2019d). Moreover, participation in different therapy programs, such as speech, occupational, and sensory integration, helps individuals with ASD with verbal communication, activities of daily living, and cope with sensory input (CDC, 2019d).

Complementary and alternative medicine. Complementary and alternative medicine (CAM) includes non-Western forms of treatment to help alleviate symptoms associated with ASD (CDC, 2019d). Some of these treatments include mind or body practices, such as massage therapy, as well as special diets (CDC, 2019d). Over 30% of children with suspected or recently diagnosed ASD was found to utilize CAM as part of their treatment, and 9% was noted to use a possible unsafe treatment, such as taking anti-infective drugs (antibiotics, antivirals, antifungals, and antiprotozoals) or cod liver oil, partaking in chelation therapy, or refusing immunizations (CDC, 2019d; Levy, Mandell, Merhar, Ittenbach, & Pinto-Martin, 2003).

Dietary modifications or supplements. Dietary approaches to treat ASD include changes to an individual's dietary pattern. According to the CDC (2019d), some children may respond well to some treatments while other children may not respond at all. Parents have observed that dietary modifications or supplements have affected the physical and emotional state of their child with ASD (CDC, 2019d). Adoption of dietary changes as a treatment for ASD stems from the belief that vitamin and mineral deficiency or food allergies contribute to manifestation of ASD symptoms (CDC, 2019d).

Pharmacological treatments. Pharmacological treatments for ASD exist for symptoms related to the developmental disability, such as depression, increased level of energy, lack of concentration, or seizures (CDC, 2019d). Two antipsychotic medications, aripiprazole (Abilify) and risperidone (Risperdal) are approved by the U.S. Food and Drug Administration for use in children between ages 5 and 16 years of age, diagnosed with ASD, and experiencing irritability that may manifest through aggression, severe temper tantrums, or self-harming acts (National Institute of Mental Health [NIMH], 2011). Other classes of medications, such as antidepressant medications and stimulant medications, have been prescribed off-label to children with ASD, as these medications treat conditions or symptoms that are similar to ASD (NIMH, 2011). Health care providers have prescribed antidepressants, such as sertraline (Zoloft) or fluoxetine (Prozac) to address various symptoms, including aggression, anxiety, and repetitive behaviors, and stimulant medication, such as methylphenidate (Ritalin), to address hyperactivity noted in children with ASD (NIMH, 2011).

Parental Beliefs and Perceptions about Autism Spectrum Disorder

Parental beliefs about the etiology of ASD range from a variety of causes, from genetic causes to immunizations. One study reported that 80% of parents associated their child's diagnosis of autism to family history, environmental influences, as well as possible genetic components (Mercer, Creighton, Holden, & Lewis, 2006). Other causal factors for the diagnosis of ASD included: (1) genetic influences—a family history of ASD or a genetic defect (90.2%); (2) perinatal factors—injury or severe trauma during birth, anoxia, fetal distress, postpartum infection, infection, respiratory infection, emergency cesarean section, postpartum oxygen requirement, premature birth, low birth weight, induced labor, premature rupture or membrane, or premature labor (68.3%); (3) dietary factors—intolerance to gluten and casein (51.2%); (4) prenatal factors—street drugs, toxemia, uterine bleeding, smoking, maternal vaccination, advanced maternal age, prescription medications, influenza, genital herpes, and upper respiratory infection (43.9%); and (5) childhood vaccinations—haemophilus influenzae type B, hepatitis B, meningitis, diphtheria/pertussis/tetanus, diphtheria/tetanus, polio, and measles/mumps/rubella (40%) (Mercer et al., 2006).

Goin-Kochel and Myers (2005) also examined parental causal beliefs of ASD from a developmental standpoint. They noted two distinct pathways of the development of the developmental disorder: (1) congenital, or arising at or near birth; and (2) regressive, or developing regressive patterns, such as normal development up until a certain point at which the child begins to revert or is unable to learn new skills (Goin-Kochel & Myers, 2005). Study participants associated a congenital cause of ASD to be genetic, whereas a regressive cause of ASD to be outside factors, such as environmental influences or childhood vaccinations (Goin-Kochel & Myers, 2005).

Kleinman's Explanatory Model of Illness

Explanatory models encompass the perceptions about illness and care from those directly affected by the illness, such as the patient, family, or health care providers (Kleinman, 1980). Kleinman, Eisenberg, and Good (1978) defines illness as a cultural, personal, or interpersonal response to discomfort or disorders, whereas disease as pathophysiological processes or psychological disorders. Similar to explanatory models from the health care provider perspective, some or all of the following five elements comprise explanatory models for illness in individuals: (1) etiology; (2) symptom onset; (3) pathophysiology; (4) illness trajectory—acute illness, chronic illness, or disability; and (5) treatment modalities (Kleinman et al., 1978; Kleinman, 1980). Kleinman et al. (1978) also noted other aspects of the explanatory model that were crucial to understand the individual's meaning and understanding of the illness from a cultural and psychosocial perspective: (6) anticipated treatment results; (7) problems aggravated by illness; and (8) fears about illness. These elements are integrated into eight open-ended questions to evoke explanatory models from individuals (Kleinman, 1980; McSweeney, Allan, & Mayo, 1997).

Kleinman (1980) emphasizes that the explanatory model give the person (e.g., ill patient, family member) an opportunity to voice not only their perspectives and interpretations about the illness, but also its impact to themselves and their families, and selection and assessment of available treatment modalities. Individuals utilize explanatory models as means for both coping with and placing meaning on the illness (McSweeney et al., 1997). Using this model in the clinical context helps the individual, family, and health care provider develop a mutual, culturally sensitive care plan that integrates personal and cultural beliefs integral to the life situation of the ill individual (McSweeney et al., 1997).

Explanatory Models of Illness and Autism Spectrum Disorder

Several studies have utilized Kleinman's explanatory model of illness as a framework for understanding ASD. Four studies were conducted in the following countries: (1) Australia; (2) Ethiopia; (3) India; and (4) Taiwan. Gray (1995) explored parental perceptions of autism using Kleinman's explanatory model of illness in 33 parents—9 fathers and 24 mothers—of a child with ASD residing in Queensland and New South Wales, Australia. Tilahun et al. (2016) examined explanatory models, coping strategies, stigma experience, needs, and treatment intervention in 102 caregivers of a child with a developmental disability—intellectual disability (ID)—68 caregivers—or ASD—34 caregivers—in Addis Ababa, Ethiopia. Sarrett (2015) explored explanatory models of illness in 32 parents of children who displayed autistic characteristics in Kerala, India, a region in which residents have high accessibility to biomedical health care. In addition, Shyu, Tsai, and Tsai (2010) explored ASD in 13 parents of a child with autism using Kleinman's explanatory model of illness in Taiwan.

Etiology

These studies reported on the etiology of ASD that included a multitude of causes, ranging from those rooted in biomedical reasons to supernatural reasons. According to Gray (1995), parental perspective of the most common causes of ASD are: (1) birth trauma, such as challenging or complicated deliveries that involved the mother being in labor for a prolonged period, the child being in breech position, or the health care provider using specialized instruments, such as forceps, during delivery; (2) congenital damage due to events during the pregnancy, such as maternal illness, vaccination, use of alcohol or drugs prenatally, or contact with radiation or chemicals prenatally; and (3) heredity, where other family members were noted to express autistic tendencies, such as "reclusive or anti-social behavior" (p. 110).

Similarly, Shyu et al. (2010) noted biological causes for ASD such as inheritance, fetal brain damage in utero, and other "unknown" etiology (p. 1327). However, Shyu et al. (2010) also attributed ASD to nutritional issues such as food allergies (e.g., egg, dairy), vitamin deficiencies (e.g., vitamins B1 and B2), heavy metal presence, and metabolic disorders. Sarrett (2015) also found that the majority of parents attributed ASD to be biomedical causes through: (1) "negative event" prenatally; (2) "negative event" at delivery; and (3) seizure activity (p. 66). Lastly, Tilahun et al. (2016) noted that developmental disorders which includes both ID and ASD were caused by the following biomedical conditions: (1) epilepsy; (2) complications during delivery; (3) head injury; (4) heredity; (5) infectious disease or pathogens; and (6) prenatal consumption of alcohol or narcotics (e.g., *catha edulis*, a stimulant).

Three population groups—Australian, Ethiopian, and Taiwanese—expressed supernatural or spiritual causes of ASD (Gray, 1995; Shyu et al., 2010; Tilahun et al., 2016). Gray (2015) noted that a few parents attributed ASD to religious or magical causes. However, many Taiwanese parents expressed supernatural causes for ASD through eliciting advice or information from fortune tellers (Shyu et al., 2010). Parental use of fortune tellers occurred when the child developed speech problems, such as absence of speech. Fortune tellers often provided explanations for these problems as based on the child's past life (e.g., being a wealthy, idle person who never verbalized hunger, but rather opened their mouth to be fed) or the child's future (e.g., predicting the child will talk at a later age once the fire blocking the child's speech dissipates) (Shyu et al., 2010). Likewise, Ethiopian caregivers of children with ID and ASD frequently attributed their behavior to supernatural causes, which included: (1) evil eye—negative repercussions, such as bad luck or injury, placed through staring at an individual; (2) curse—invoking punishment or harm to another person through supernatural means; (3) punishment from God; (4) sinful act—an act committed by the caregiver which subsequently affected the child; or (5) possession by spirit—a spirit enters the child to control his or her actions and thoughts (Tilahun et al., 2016). Sarrett (2015) noted that study findings reported no caregiver expressed supernatural or spiritual explanations as causes for ASD. Caregivers generally linked the child's problem to various reasons, such as a Western researcher for the study as well as exposure to Western modalities of treatment.

Symptom Onset

Studies reported ASD symptom onset occurred during early childhood in the Australian and Taiwanese populations (Gray, 1995; Shyu et al., 2010). Gray (1995) found that 24 parents observed symptoms of ASD prior to 30 months of age, where 8 children expressed symptoms between birth and 6 months of age. In the Taiwanese population, most parents observed their child had symptoms between 18 to 24 months of age, but reports ranged from birth to 36 months of age (Shyu et al., 2010). Symptoms of ASD found in both Australian and Taiwanese populations included: (1) tantrums; (2) feeding challenges; (3) speech delay; (4) poor eye contact; (5) social interaction challenges; (6) disruptive behaviors; (7) motor delay; and (8) unusual behaviors, such as rocking, hitting head, spinning, or hand-flapping (Gray, 1995; Shyu, 2010). In the Australian population, Gray (1995) also found that parents reported seizures, rigid body posture, hyperthyroidism, toileting issues, and language regression or loss. In the

Taiwanese population, parents observed that the child with ASD exhibited varying energy levels—low or high—and lack of interest in the setting or environment (Shyu et al., 2010). The Ethiopian and Indian population study did not address ASD.

Illness Trajectory

Regarding ASD illness trajectory, the Australian, Taiwanese, and Ethiopian populations had varying perspectives about the illness trajectory for a child with ASD or a child with ID or ASD, respectively. In the Australian population, the majority of parents, with one exception of a parent whose child's ASD symptoms dramatically improved, believed that their child would not fully recover from the developmental disability and would warrant being unemployed and residing in a halfway home later in life (Gray, 2010). Taiwanese parents, however, expressed concern, worry, and uncertainty in terms of their child's integration into mainstream society, and general rights, such as voting and inheritance (Shyu et al., 2010). Moreover, parents felt strained relationships with the child with ASD due to communication barriers and thus left parents feeling not confident and inadequate in their parenting roles and skills (Shyu et al., 2010). Family relations were also affected as parents expressed guilt for lack of time or energy for other children, as well as marital strain amongst partners in balancing parenting duties and completing household duties (Shyu et al., 2010).

In contrast, 92.2% of Ethiopian caregivers of children with ID or ASD believed that the child could be cured, although 43.1% believe that the child's disability was severe (Tilahun et al., 2016). Many of the caregivers also believed that ID or ASD is not transferrable to others (93.1%). In addition, the caregivers believed that others also perceived that ID or ASD are not transferrable to others (88.2%) (Tilahun et al., 2016). Illness trajectory was not addressed in the Indian population.

Treatment Modalities

Treatment modalities for ASD in the Taiwanese and Indian populations exercised biomedical treatment and traditional medicine (Shyu et al., 2010; Sarrett, 2015). According to Shyu et al. (2010), most parents sought therapy (e.g., occupational, speech), sensory integration, and enrollment in a specialized day care program for their child with ASD. Other means of treatment utilized taking vitamin supplements and addressing food allergies, as well as traditional treatments, including acupuncture or detoxification therapy (Shyu et al., 2010). Supernatural strategies of treating ASD were also employed, such as eliciting assistance from a Buddhist monk to intervene for healing through recitation of Buddhist texts, or transforming the destiny of the child through a name change (Shyu et al., 2010). Within the Indian population, parents primarily sought biomedical, Western-influenced treatment through the hospital or clinic, as many physicians in Kerala trained at Western medical schools (Sarrett, 2015). However, despite the Western biomedical influences, 75% of the research participants utilized other treatment modalities that spanned from traditional medicine, such as homeopathy and Ayurveda, and religious or spiritual practices, such as using amulets, prayers, and rituals (Sarrett, 2015).

Traditional medicine and biomedical treatment were pursued by the Ethiopian population to address ID and ASD (Tilahun et al., 2016). The majority of caregivers (54.9%) utilized traditional medicine prior to seeking biomedical help (45.1%) (Tilahun et al., 2016). Such traditional medicine included use of holy water, going to mosques or churches, or seeing traditional healers, such as sorcerers, herbalists, traditional physical therapists, and healers in the Orthodox Christian community (*Debtera*) or Muslim community (*Kalicha*). In addition to seeking help at a mental health clinic, caregivers sent the child with ID or ASD to hospitals, clinics, public health facilities, and pharmacies for treatment (Tilahun et al., 2016).

Management of Care for a Child with Autism Spectrum Disorder

Three studies addressed management of care for a child with ASD in terms of management of the child's health care needs and management of the parental role. Strunk, Pickler, McCain, Ameringer, and Myers (2014) examined how 12 parents of an adolescent with ASD managed their adolescent's health care needs in the Eastern region of the United States. Tsai, Tsai, and Shyu (2008) examined management of health care needs of a child aged 3 to 7 years with ASD in Taiwan from 12 maternal perspectives. In addition, Safe, Joosten, and Molineux (2012) explored the maternal role in caring for a child with ASD in Western Australia through interviews of 7 mothers of a child aged 6 to 12 years with ASD.

Management of Health Care of an Adolescent with Autism Spectrum Disorder

The management of health care for an adolescent with ASD in the United States was described as "parents needing assistance," as parents experienced a lack of guidance in caring for their child's needs (Strunk et al., 2014, p. 331). These parents experienced distress from a variety of issues: (1) helplessness arising from a dearth of information and resources, where parents had to take a proactive approach to learning how to care for their adolescent with ASD; (2) not being heard by health care providers about their concerns, such as long-term medication effects; (3) lack of appropriate ASD-specific services, such as paucity of trained medical professionals in ASD, interprofessional collaboration of health care services, and inadequate insurance to cover specialized treatments and therapy; and (4) increased concerns about non-ASD conditions and symptoms, such as toileting, sleeping, dental care, and behavioral outbursts (Strunk et al., 2014). Moreover, parents were highly concerned about various aspects of health care and delivery, such as medication administration and adherence, strategies to care for adolescents with ASD in the health care setting (e.g., dental visits, pre-operative preparation), safely caring for the adolescent with complex medical needs in addition to ASD (e.g., seizure disorder, insomnia), and request for increased, specialized assistance, resources, and support for families of adolescents with ASD (Strunk et al., 2014). Overall, the parental experience revolved around managing care of their adolescent with ASD without clear guidance or support after diagnosis (Strunk et al., 2014).

Management of Maternal Role in Caring for a Child with Autism Spectrum Disorder

"Integrating the nurturer-trainer roles," was the process in which Taiwanese mothers of a child with ASD used to manage their child's health care (Tsai et al., 2008, p. 1802). This process utilized strategies in which mothers simultaneously balanced a dual role as nurturer (e.g., comforting child) and trainer (e.g., teaching child skills) (Tsai et al., 2008). Four elements constituted this process: (1) exploring effective treatment strategies for the child with ASD (e.g., behavioral therapies, alternative medicine); (2) modifying expectations for the child with ASD (e.g., attaining a realistic perspective of the child's abilities rather than comparing child to typically-developing children); (3) moderating conflicts that may arise while being both a nurturer and trainer (e.g., wanting to nurture and care for the child during therapies while trying to adhere to therapy protocol); and (4) creating competencies for the nurturer and trainer roles (e.g., seeking out appropriate professional resources to help one become a nurturing parent while implementing behavioral training that is effective) (Tsai et al., 2008).

Through "integrating the nurturer-trainer roles," mothers experienced several experiences in role development: (1) role strain—the inability to serve as both the nurturer and trainer (e.g., some mothers felt increased strain when one role was more challenging than the other); (2) role preparedness—the extent of preparedness to manage care for a child with ASD (e.g., increased sense of confidence to handle challenging situations); and (3) emotional reaction—mixed feelings that arise while juggling the nurturer and trainer roles (e.g., rewarding, joy, frustration, sadness) (Tsai et al., 2008). Lastly, mothers used four different strategies to integrate being a nurturer and trainer for their child: (1) training-insisting—emphasizing on training the child with various behaviors (e.g., eating patterns); (2) going-along—prioritizing nurturing the child based on their needs and progress (e.g., not forcing a child to engage in training activity he dislikes or when tired); (3) strength-facilitating—focusing on the child's strength to optimize abilities; and (4) trying-it-all—using all avenues of treatment to promote child's development (Tsai et al., 2008).

Similarly, Safe et al. (2012) explored various aspects of management of a child with ASD—daily maternal role, child's behavior and treatment, and personal emotions. From the personal interviews, mothers experienced the following: (1) "mother as therapist"—becoming a therapist in addition to a mother, where the mother also undertakes behavioral therapy for their child in addition to daily parenting; (2) "something's got to give"—challenges in maintaining other roles, such as being a spouse, which may lead to negative outcomes (e.g., divorce); (3) "the frustration of finding the right support"—grappling to seek an effective and caring support system that empathize with the challenges of raising a child with ASD, but does not solely revolve around ASD, and floundering to find appropriate educational services for their child; and (4) "a paradox of emotions"—simultaneously lamenting the loss of a typically-developing child while unconditionally loving their child (Safe et al., 2012, p. 297-299).

Autism Spectrum Disorder and Asian Americans

Parenting a child with ASD posits challenging situations due to the complexity and severity of the developmental disability (Luong, Yoder, & Canham, 2009). Although much research has focused on ASD and its implications for caregiving, little research has focused on

Southeast Asian populations (Luong et al., 2009). Compared to American culture, Southeast Asian groups are unique in their interdependency with family members—both immediate and extended—in their daily living (Luong et al., 2009). Within the Filipino culture, the notion of community is valued in childrearing processes, where extended family and community members are influential and supportive figures (Santos & McCollum, 2007). In the Philippines, raising a disabled child is stigmatized within the community as the disability is attributed to "supernatural or religious causes" (Santos & McCollum, 2007, p. 245). Unlike care provision in the United States, early intervention programs in the Philippines are not mandated by the public health care system, and services must be sought via private hospitals and clinics (Santos & McCollum, 2007). A study of Filipino mothers of developmentally disabled infants and toddlers in the Philippines suggested that they learned how to interact with their child through other individuals, such as professionals or family members (Santos & McCollum, 2007). A dearth of research about ASD in Asian Americans, particularly Filipino Americans, is noted.

Filipino American Culture

Historical Context

The Philippines is a Southeast Asian archipelago comprised of approximately 7,107 islands in the Pacific Ocean (DeGracia, 1979; Posadas, 1999). This country is comprised of three different regions—the northernmost region, Luzon, the central region, Visayas, and the southernmost region, Mindanao (Posadas, 1999). Filipinos are of Malayan descent and heavily influenced by Spanish, Chinese, and American cultures (Anderson, 1983; DeGracia, 1979). Spanish colonization began in 1521 with Ferdinand Magellan, a Portuguese explorer who arrived to the Philippine Islands and lasted until the Spanish-American War in 1898, where the country surrendered to the United States for $20 million (DeGracia, 1979). Chinese influence began during the 17th century, where trading occurred between the two countries (DeGracia, 1979). These historical events are highly instrumental in the development of these sites, as many Filipinos have roots embedded in Spanish and Chinese values, as well as American influences (DeGracia, 1979).

Colonial Mentality

Colonial mentality, or "internalized oppression," (p. 1) is found in the Filipino and Filipino American population due to historical roots of colonization (David & Okazaki, 2006). This set of attitudes brings forth ramifications to psychological well-being, as a power struggle may manifest between the oppressed population and the dominant group that may lead to feelings of devaluation of self and culture (David & Okazaki, 2006). In the Filipino American culture, colonial mentality exists as a complex construct that may present through a variety of ways: (1) belittlement of Filipino ethnic identity; (2) bias against Filipino Americans who are acculturated to a lesser degree; (3) embracement of a positive perception of the colonizing group; and (4) perception of American and Spanish cultures as superior to Filipino culture (David & Okazaki, 2006). Traces of colonial mentality are embedded in contemporary Filipino culture, especially through language and religion that are not native to the country, as American influence marked English as one of two official languages of the Philippines—the other is Filipino, heavily based on the Tagalog dialect—and Spanish influence brought forth Catholicism as the dominant belief system in the Philippines (David & Okazaki, 2006).

Traditional Filipino Values

Traditional Filipino values are rooted in interpersonal relationships and communication patterns. Many of these values are adapted from other cultures, including Spanish, Chinese, and Japanese cultures (DeGracia, 1979).

Primary values. According to Nadal (2011), there are four primary traditional Filipino values: (1) *pakikisama*; (2) *hiya*; (3) *utang ng loob*; and (4) *kapwa*. *Pakikisama,* or getting along with others, involves a great degree of agreeability with others (DeGracia, 1979). Filipinos will readily be in agreement or in solidarity with others, despite any challenges or inconveniences that the situation may bring forth (DeGracia, 1979). *Hiya,* or shame, is a cultural sentiment—also found in Chinese, Japanese, and Spanish cultures—that emerges when an individual is unable to uphold societal norms in front of authoritative figures or community members (DeGracia, 1979). For instance, a Filipino woman may experience *hiya* from an unplanned pregnancy outside of wedlock.

Utang ng loob, or reciprocal obligation, is a Filipino value that embeds reciprocity in relationships when an individual requests assistance from others or accepts a service offered from others (Nadal, 2011). For example, if an individual without a car was offered and accepted a ride home from their colleague, there is a sense of *utang ng loob,* where the individual would reciprocate the favor to their colleague through providing money for gasoline or offering food. *Kapwa,* or togetherness, embodies strong bonds with other Filipinos on multiple levels—emotional, interpersonal, and spiritual—regardless of the degree of the relationship (e.g., acquaintance, family, friend, or stranger) (Nadal, 2011). Filipinos often connect with other Filipinos in social settings, such as in the workplace or public places, due to their shared ancestry that forms a basis for conversations (Nadal, 2011). With high regard placed on interdependence and mutual support, Filipinos embrace collectivism, where group needs are prioritized over one's own needs (Patacsil & Skillman, 2006; Triandis, 1995).

Secondary values. Two secondary traditional values exist in the Filipino culture: (1) *lakas ng loob*; and (2) *bahala na* (Nadal, 2011). *Lakas ng loob,* or internal resilience, exudes hardiness in challenging or difficult situations, and uncertain or questionable circumstances (Nadal, 2011). Such fortitude helps an individual conquer and cope with challenges (Nadal, 2011). *Bahala na,* or placing matters into God's hands, rather than taking control over a situation (DeGracia, 1979; Nadal, 2011). This fatalistic nature influences an individual through a sense of acceptance of the situations they are in, as well as a carefree attitude towards life (Nadal, 2011). For instance, an individual diagnosed with a terminal illness would accept their illness as part of God's will (DeGracia, 1979). Although the individual may experience suffering or challenges during the course of the illness, they believe that the diagnosis was in God's best intention, attributing to being resigned to the illness and quiet tolerance of the situation (DeGracia, 1979).

Spanish-influenced values. Filipino values have been greatly impacted by many years of Spanish colonization. *Amor propio,* or self-esteem, encompasses a sense of respect for oneself and commands perception of oneself in high regard (DeGracia, 1979; Nadal, 2011). In a situation where an individual's *amor propio* is inflicted, such as humiliation, self-pride is subsequently wounded, and an individual demonstrates upholding composure through distance or silence to save face (DeGracia, 1979). A clinical encounter that illustrates this cultural value involves a Filipino elderly patient who nods in silence to protect their *amor propio* after their health care provider reprimands them for non-compliance to their hypertension medications. Another Spanish-influenced value, *personalismo,* or "interpersonal relationships" (p. 47) is inherent in communicative patterns, as Filipinos approach social interactions with a warm, hospitable demeanor (Nadal, 2011). Unique to this ethnic group, *personalismo* embraces an affectionate closeness with others, such as greeting another individual with a hug or kiss (Nadal, 2011). This display of warmness is unconventional in other traditional Asian cultures, where a rational, logical, unemotional form of communication is favored (Nadal, 2011; Okamura & Agbayani, 1991).

Traditional Filipino Health Beliefs and Perceptions

Traditional Filipino health beliefs and perceptions are rooted in various cultural influences over many centuries (Orque, 1983). These traditional health beliefs and perceptions are a composite of folk traditions found in American, Arabian, Chinese, Indian, Malay, Mexican, and Spanish cultures (McKenzie & Chrisman, 1977).

Historical Influences

Prior to Spanish colonization, *anting-anting*, or amulets, utilized as good luck charms or protection from *kulam*, or witchcraft (Orque, 1983). Since Spanish colonization, these *anting-anting* are currently presented as Catholic religious items, lockets, religious medals, and scapulars (Orque, 1983). Due to historical events, there is much semblance between the health beliefs and perceptions of Filipinos and Latinos, particularly in humoral pathologies (Orque, 1983). Moreover, American colonization of the Philippines also led Filipinos to adopt Western ideologies of health and illness and contemporary health services and facilities (Orque, 1983). As a result, a hybrid of traditional healing and Westernized medicine are integrated into health care services of Filipinos residing in the Philippines and in the United States (Orque, 1983).

Supernatural and Natural Causes of Illness in Filipino Culture

From the traditional standpoint, disease etiology is based on various causes as opposed to a "one-cause/one-effect pattern" (Orque, 1983, p. 160). Filipinos characterize disease etiology in one of two ways: (1) natural or physical and (2) supernatural (McKenzie & Chrisman, 1977; Orque, 1983). Natural or physical disease etiology include: (1) excessive anxiety; (2) excessive food intake; (3) excessive exposure to heat, cold, and rain; (4) excessive work; (5) lack of food or sleep; and (6) unsanitary environment (Orque, 1983). Supernatural etiology is due to either: (1) a curse placed by environmental spirits, evil individuals, souls of the deceased, or witches; or (2) a sanction or punishment from God (Orque, 1983). To negate illness caused by supernatural forces, an individual may utilize amulets, prayers, and talismans in the belief that physicians do not have the capacity to heal individuals with supernatural-induced conditions (McKenzie & Chrisman, 1977). Additionally, Filipinos may seek folk healers to cure illness as they have divine powers through connections with supernatural forces to sway various aspects of life, such as healing those with addictions, such as alcoholics, and psychiatric illness, blessing individuals with success in their professional and personal lives, and influencing social connections in a positive manner (McKenzie & Chrisman, 1977). Despite the effects of acculturation, Filipino immigrants uphold such traditional health beliefs and perceptions (Orque, 1983), and may draw upon these cultural etiologies at "unexpected times" (Anderson, 1983, p. 815).

Comparison of Western and Filipino Beliefs about Illness

Causal effects of disease or illness in Filipino culture are not based on a Western biomedical standpoint (Orque, 1983). From a Western perspective, illness is a result of exposure to bacteria or viruses, as opposed to traditional Filipino beliefs, where illness ensues from *tiyempo* or timing—a combination of an individual's increased predisposition to illness coupled with outside uncontrolled factors (Orque, 1983). For example, an individual may become ill from the combination of the state of *pagod*, or fatigue, and exposure to precipitation (Orque, 1983). A related causal factor is *panahon*, or time or weather, where specific transient events (e.g., era, menstrual period, season, time, or weather) may trigger illness (Orque, 1983).

Timbang, or balance, is a core principle in the health beliefs and perceptions of Filipinos (Anderson, 1983). Based on this principle, health is maintained when balance is attained, whereas illness occurs when an imbalance persists (Anderson, 1983). Such imbalance is embedded in the Greek Hippocratic Theory of Pathology, where the disharmony of four humors, or bodily fluids—black bile, blood, yellow bile, and phlegm—results in illness in an individual (Orque, 1983). Each bodily fluid is associated with two characteristics—(1) either hot or cold or (2) either wet or dry (Monrroy, 1983). Based on this theory, black bile is cold and dry, blood is hot and wet, yellow bile is hot and dry, and phlegm is cold and wet (Monrroy, 1983). Remedies for illness and disease require achieving equilibrium between these elements through adding or removing heat, cold, dryness, or wetness from the body (Monrroy, 1983).

As a derivative of the Hippocratic Theory of Pathology, the notion of hot and cold is central to health maintenance and illness prevention (Anderson, 1983; Monrroy, 1983; Orque, 1983). Illness is manifested in sudden imbalances between hot and cold areas of the body or dietary intake (Anderson, 1983; Orque, 1983). For example, *masisikmura*, or diaphragmatic cramping, may ensue upon intake of cold food or drink when waking up in the morning, as it is an insult to a vulnerable, overheated state after awakening from sleep (Anderson, 1983). Similarly, the body is in a vulnerable state when muscles are fatigued, such as after ironing and *rayuma*, or rheumatoid arthritis, may occur if an individual washes or bathes in cold water (Anderson, 1983; Orque, 1983). On the other hand, good health is achieved through avoiding extremes, like hot or cold, and staying warm (Anderson, 1983). Warmth can stem from maintaining a stout physique or retaining baby fat to preserve “vital strength” and act as a protective mechanism from illness (Anderson, 1983, p. 815).

Congruent with the hot and cold theory, health is shaped by the balance and quality of *hangin* or wind within the individual (Anderson, 1983). Bodily systems are disrupted through exposure to abrupt gusts of cold air (Anderson, 1983; Orque, 1983). Rheumatologic conditions, such as rheumatism, and respiratory illnesses, such as colds and pneumonia, arise from entrance of *hangin* into the body (Anderson, 1983). Balance disruption induced by *hangin* may also manifest through changes in weather (e.g., long periods of rain followed by intense heat) and changes in season (e.g., start or end of monsoons) (Anderson, 1983). For instance, intense heat and "rising vapors," or evaporation from soil, may trigger fever, pain, or disorientation—manifested in incoherence and disorientation (Anderson, 1983). *Hangin* may also be induced by particular food and drink intake, consequently generating disequilibrium.

Women and children may be vulnerable to the effects of *hangin*. During the postpartum period, women protect themselves from entrance of "bad air" through avoidance of bathing for at least five days after childbirth, and exposure to *hamog*, or cold wind, through bundling in warm clothing and blankets, as the body is recuperating from the loss of heat from delivery (Anderson, 1983; Orque, 1983, p. 160). Children exposed to evaporation from soil while playing in either direct heat or in shaded areas may experience *rayuma* or disorientation, indicative of the separation of the soul from the body (Anderson, 1983). Treating this disorientation requires reunification of the soul and body through two means: (1) continually reciting the child's name or (2) consulting an expert practitioner (Anderson, 1983).

Personal hygiene is highly esteemed as a means to convey health and save face (Anderson, 1983). Individuals who exude an unkempt appearance are described as *burara* or untidy or cluttered, and considered careless or irresponsible (Anderson, 1983). Health is sustained through frequent bathing and cleansing oneself after voiding (Anderson, 1983). Illness may display if bathing is inconsistent (Anderson, 1983). Therapeutic baths comprised of warm or cool water infused with herbs are utilized to reestablish equilibrium in the body (Anderson, 1983).

As a central tenet in Filipino health beliefs, balance is perceived to promote stable health, whereas imbalance through negatively perceived behaviors, such as being immoral, reclusive, uncontrolled, or untidy, brings forth accident, illness, or misfortune (Anderson, 1983). Akin to karma, Filipinos perceive that their actions influence future experiences via divine retribution (Anderson, 1983). Other sources of illness may include inconsistent eating and sleeping patterns (Anderson, 1983). Psychological or emotional symptoms, including anxiety, grief, low self-esteem, stress, worry, may serve as predisposing factors to illness (Anderson, 1983). Imbalance may also result from disturbing situations, such as having nightmares, abrupt awakening from deep sleep, or being frightened (Anderson, 1983).

Explanatory Models of Illness in Filipino and Filipino Americans

To this date, no studies have explored ASD in Filipino or Filipino American culture. However, two studies have examined chronic illness or congenital defects in Filipino and Filipino Americans through the lens of the explanatory model of illness. Although these studies differ in illness or disease process studies, both studies glean into explanatory models of illness in the context of culture.

Filipino Americans and Hypertension

Dela Cruz and Galang (2008) explored personal beliefs and perceptions about hypertension in bilingual Filipino American adults aged 18 years or older residing in Los Angeles and San Diego, California counties. This qualitative study utilized focus groups to elicit individual beliefs and perceptions about hypertension using Kleinman's explanatory model of illness.

Etiology. Regarding the etiology of hypertension, Filipino Americans suggested that several contributing factors were involved: (1) stress; (2) physical inactivity; (3) Filipino cuisine;

(4) risk taking behavior (e.g., alcohol and tobacco); and (5) heredity (dela Cruz & Galang, 2008). Stress affected Filipino American adults through various avenues, including discrimination faced from language barriers (e.g., speaking with accent) or cultural communication styles (e.g., practicing values of *pakikisama,* getting along with others and *mahiyain,* staying reserved, through lack of verbalizing personal thoughts or feelings for fear of conflict with others) (dela Cruz & Galang, 2008). Lack of physical activity or exercise is due to accessibility to various transportation modes in the United States. For example, walking is a primary mode of transportation in the Philippines, whereas in the United States, vehicles are the primary mode of transportation. Nannies or helpers are employed for chores or babysitting in the Philippines during limited time periods during the day, whereas those in the United States respond to limited time by completing all tasks or errands by oneself (dela Cruz & Galang, 2008).

Research participants also expressed that Filipino cuisine is laden with fat and sodium (dela Cruz et al., 2008). For example, traditional condiments used in daily cuisine for seasoning, such as *bagoong* (fermented fish) or *patis* (liquid from fermented fish) have high levels of sodium and traditional dishes are high in cholesterol, such as *lechon* (roasted pig), or fat, such as *lumpia* (fried eggroll with meat and/or vegetables) (dela Cruz & Galang, 2008). Moreover, traditional beliefs about food and cuisine permeate social interactions, as it is considered insulting if a guest does not eat food offered by the host at a party, and it is a challenge to control portions when it is socially acceptable to share food during mealtime (dela Cruz & Galang, 2008). Filipino Americans alluded that food availability in the Philippines differed from the US, as meat is more accessible in the United States due to lower prices. Thus, more fish and vegetables were consumed in the Philippines, which are more nutritious and healthier (dela Cruz & Galang, 2008). The research participants did not elaborate further on risk taking behavior and heredity, although mentioned these two factors as salient to the etiology of hypertension (dela Cruz & Galang, 2008)

Symptom onset. A myriad of reasons for hypertension symptoms and causes were provided by Filipino Americans (dela Cruz & Galang, 2008). Such symptoms included the following: (1) pain in various areas—chest, eye, and/or neck; (2) numbness in various areas—hand and/or mouth; (3) visual changes (e.g., blurred vision); (4) headache; (5) lightheadedness; (6) dizziness; (7) irritability; (8) palpitations; (9) involuntary movement (e.g., cheek twitching); and (10) shortness of breath (dela Cruz & Galang, 2008).

Pathophysiology. Research participants relayed that salt and water played an important role in how hypertension manifests in the Philippines and in the United States (dela Cruz & Galang, 2008). A general belief that "salt attracts water" exists, where the consumption of salt leads to water retention (dela Cruz & Galang, 2008, p. 122). The hot and humid climate in the Philippines yields to individuals sweating, which causes salt and water to excrete from the body (dela Cruz & Galang, 2008). To the contrary, the United States lends to a sedentary lifestyle with jobs that may not be as labor-intensive and offer air-conditioned environments, and prevents individuals from sweating as much, which causes salt and water to remain in the body and increases blood pressure (dela Cruz & Galang, 2008).

Illness trajectory. As a chronic condition, the research participants were cognizant about various complications that may arise from hypertension (dela Cruz & Galang, 2008). Some of these complications include the following: (1) stroke; (2) heart attack; (3) renal disease; (4) disability; and (5) death (dela Cruz & Galang, 2008).

Treatment modalities. Research participants noted treatment of hypertension through a biomedical perspective, but also integrated alternative treatments that employed home remedies (dela Cruz & Galang, 2008). Biomedical treatment of hypertension included the following: (1) smoking cessation; (2) decrease alcohol consumption; (3) hypertension medication adherence; (4) engage in regular physical activity; (5) maintain healthy weight; and (6) reduce intake of high sodium and high fat foods (dela Cruz & Galang, 2008). Medication adherence often posed a challenge for this Filipino American population, as side effects of antihypertensive medication included gastrointestinal symptoms (e.g., diarrhea and vomiting), genitourinary symptoms (e.g., increased urination and decreased libido), and headaches (dela Cruz & Galang 2008). Additionally, female participants expressed that it was challenging to remember taking the medications due to a demanding schedule and familial responsibilities (dela Cruz & Galang, 2008).

Alternative treatments for hypertension included home remedies, such as consuming teas from various plants and/or fruit (e.g., garlic, ginger, guava, lemongrass, or mango leaves), creating poultices from various plants and/or fruit (e.g., coconut oil, ginger, or guava leaves), and drinking *pito-pito* (a seven-ingredient tea comprised of leaves from pandan, guava, mango, banaba, and alagaw, and seeds from anise and coriander) *and noni juice* (juice from an evergreen tree found in tropical regions) (dela Cruz & Galang, 2008). Other treatments for hypertension include seeking help from a *hilot,* a folk healer specializing in massage therapy, as well as an acupuncturist (dela Cruz & Galang, 2008). Moreover, individuals sought several means of coping with the chronic illness though spirituality and humor (dela Cruz & Galang, 2008).

Illness management. Hypertension management was heavily influenced by certain individuals (dela Cruz & Galang, 2008). Individuals most helpful to those with hypertension included immediate family members—spouse, significant other, or children (dela Cruz & Galang, 2008). They positively influenced both male and female research participants through encouraging a low sodium and low-fat diet and reminding the research participant to take their prescription medicine. Female participants noted that family members were helpful with assisting with household duties and chores and checking their blood pressure, but were not helpful when being demanding of their time (dela Cruz & Galang, 2008). Male participants noted that their spouse was helpful in maintaining a "peaceful home," and to limit food intake (dela Cruz & Galang, 2008).

Filipinos and Cleft Lip with or without Cleft Palate

Daack-Hirsch and Gamboa (2009) explored Filipino explanatory models of cleft lip with or without cleft palate in Negros Occidental, Philippines. According to the CDC (2019b), cleft lip and cleft palate are birth defects that arise during prenatal development in which there is an opening in the lip, the palate, or both. Cleft lip may manifest as a unilateral or bilateral opening in the upper lip that may range in size from being small (e.g., indentation) or large (e.g., opening from lip into bottom of nostril) (CDC, 2019b). Cleft palate may occur as an opening in the soft palate, hard palate, or both (CDC, 2019b). As a result, the child will experience difficulties with speech, hearing, and feeding, as well as challenges with dental care (CDC, 2019b).

Explanatory models about the etiology of cleft lip with or without cleft palate were elicited from three groups—individuals with cleft lip with or without cleft palate, individuals without cleft lip or cleft palate, and health care workers in order to attain a broad perspective about the birth defect (Daack-Hirsch & Gamboa, 2009). The research recruited working class individuals, those who are unemployed, worked in low wage positions and may or may not be entitled to benefits, and well as health care workers employed in various locations, such as rural or urban health centers (Daack-Hirsch & Gamboa, 2009). Eighty individuals were included in this study—27 individuals with individuals with cleft lip with or without cleft palate, 31 individuals without cleft lip or cleft palate, and 22 health care workers.

Etiology and symptom onset. Research participants noted four different causes of cleft lip with or without cleft palate: (1) "cravings"; (2) genetics; (3) "force to the fetal face"; and (4) environmental factors (Daack-Hirsch & Gamboa, 2009, p. 127). Only individuals with cleft lip or without cleft palate and individuals without cleft lip or cleft palate noted that cravings caused the birth defect (Daack-Hirsch & Gamboa, 2009). In Filipino culture, "cravings" can be defined as a vulnerable time period during early pregnancy or first trimester in which the mother and/or father of the unborn child spent time is fixated on an object or a person, such as thinking about an individual with cleft lip with or without cleft palate or teasing an individual with cleft lip with our without cleft palate, and the unborn fetus takes upon this object's or person's attributes (Daack-Hirsch & Gamboa, 2009). The majority of research participants stated that cleft lip with or without cleft palate was caused by genetics, as inheritance patterns were noted in families through being present in the "blood" (Daack-Hirsch & Gamboa, 2009, p. 127).

External forces upon the mother's abdomen or fetal positioning, called "force to the fetal face," was reported as a cause for the birth defect (Daack-Hirsch & Gamboa, 2009). Such external forces included the following: (1) pregnant woman falling; (2) pregnant woman slipping; (3) pressure on prenatal abdomen (e.g., force of pressure upon fetus that caused opening of lip and or palate); and (4) abortion attempt (e.g., medications that induce abdominal cramping, instruments used for abortion, such as a catheter, or abdominal massage by *hilot*) (Daack-Hirsch & Gamboa, 2009). Fetal positioning could also cause cleft lip with or without cleft palate through the positioning of thumb and fingers in utero (Daack-Hirsch & Gamboa, 2009). For instance, if the thumb and fingers were positioned inside or outside of the mouth, an unexpected movement of the pregnant mother early in the third trimester may place force upon the abdomen, which in turn could open the lip or palate and consequentially form the birth defect (Daack-Hirsch & Gamboa, 2009). Environmental factors include the following: (1) malnutrition; (2) infection (e.g., chicken pox); (3) risk taking behaviors (e.g., smoking, drinking); (4) pollution; (5) stress; (6) vitamins (e.g., lack or excess); and (7) medications (e.g., birth control pills) (Daack-Hirsch & Gamboa, 2009). Research participants also alluded to “God’s will” as a cause of cleft lip and or cleft palate (Daack-Hirsch & Gamboa, 2009, p. 129).

Treatment modalities. The preferred mode of treatment for cleft lip with or without cleft palate was surgery (Daack-Hirsch & Gamboa, 2009). However, two mothers of individuals with cleft lip or without cleft palate also expressed that feeding took additional time due to the birth defect.

Preventive measures. Research participants noted that cleft lip with or without cleft palate could be prevented by several means: (1) consuming of prenatal vitamins; (2) protecting the pregnant mother from falling or having pressure placed on the abdomen; and (3) engaging in family planning to prevent future pregnancies with a fetus affected with cleft lip and or cleft palate (Daack-Hirsch & Gamboa, 2009). Additionally, research participants noted that environmental measures could protect the onset of cleft lip and or cleft palate during—not prior to—pregnancy, such as attending regular prenatal appointments, engaging in physical activity, refraining from tobacco use or alcohol consumption, taking vitamins, and eating healthy food (Daack-Hirsch & Gamboa, 2009).

Acculturation and Autism Spectrum Disorder

Acculturation

Acculturation exists as a process in which an individual adapts behaviors and/or attitudes from a different culture (dela Cruz, Padilla, & Butts, 1998; Moyerman & Forman, 1992). This process is fluid in nature, where features of both the original and host cultures are retained, renounced, or adapted (Anderson et al., 1993; dela Cruz et al., 1998; Sodowsky & Plake, 1992). There are multiple degrees of acculturation; (1) low acculturation, where an individual keeps values of their original culture and renounces values of their host culture; (2) “mid” acculturation, where an individual views both the original culture and their host culture equally; and (3) high acculturation, where an individual adapts values of their host culture and renounces values of their original culture (dela Cruz et al., 1998).

Acculturation is captured through two aspects—attitude and behavior (dela Cruz et al., 1998; Moyerman & Forman, 1992). Attitude is viewed through ethnic loyalty, a social component in which an individual identifies with a certain ethnic group (dela Cruz et al., 1998; Moyerman & Forman, 1992; Padilla, 1980). Behavior is gauged by cultural awareness, which includes a preference towards a certain culture or a use of a particular language (Anderson, 1993; dela Cruz et al., 1998). Various elements determine the level of acculturation of an individual. Individuals who have a higher level of acculturation have lived in the host country for a longer period of time, have a higher level of education, and a higher socioeconomic status (dela Cruz, 1998). Individuals who have a lower level of acculturation have immigrated to the host country at a later age, identify as first-generation immigrants, and prefer food from their original culture (dela Cruz, 1998). Mixed findings are reported with acculturation and gender, where some studies note that men and women have no significant difference in acculturation, while other studies note that men acculturate faster into the host country than women do (dela Cruz et al., 1998).

Acculturation and Autism Spectrum Disorder

No studies have been conducted in Filipino Americans, acculturation, and ASD. However, a qualitative study conducted on attitudes and knowledge about ASD in the Hispanic population in the Southwest region of the United States (Voelkel, LeCroy, Williams, & Holschuh, 2013). The authors developed a 53-item questionnaire, the Autism Awareness Survey, which captured how individuals understood and perceived ASD on various levels, such as perceptions towards health services for ASD, characteristics of individuals with ASD, awareness about individuals with ASD, and levels of acculturation (Voelkel et al., 2013). Most surveys completed were in Spanish (108 surveys), while the remaining surveys were in English (61 surveys) (Voelkel et al., 2013). Highly acculturated Hispanics reported reading about ASD in newspapers and magazines compared to less acculturated Hispanics (Voelkel et al., 2013). Those with lower levels of acculturation viewed individuals with ASD less negatively, experience increased barriers for health care access, and have less knowledge base about ASD compared to those with higher levels of acculturation (Voelkel et al., 2013). Based on the study findings, more cultural information about ASD is warranted as well as awareness of language as a barrier to attaining health care and services for individuals with ASD (Voelkel et al., 2013).

Gaps in the Literature

Through the review of literature, a dearth of knowledge exists about Filipino American child health and ASD at-large. Although studies have been conducted about explanatory models of illness in the Filipino and Filipino American community, these studies have focused on medical issues, such as hypertension, and birth defects, such as cleft lip with or without cleft palate. Such studies provide insight into Filipino culture and traditions that shape how these conditions are perceived and treated. However, ASD is a developmental disability without a cure, and treatment is not standardized, but rather catered toward each patient. The progression of ASD occurs on a spectrum and no two children are alike in their illness trajectory and their treatment plan. Although the literature suggests both biomedical and supernatural causes for ASD, it is difficult to ascertain the etiology of the developmental disability in Filipino Americans. According to Javier, Huffman, and Mendoza (2007), it is perceived that behavioral patterns of a child are closely related to family upbringing. Thus, behavioral-related issues, such as psychiatric, mental illness, or developmental delay, may be tied to families and consequently stigmatized in the community to the point where treatment is delayed (Javier et al., 2007). The family is central in Filipino American culture, and greatly influences how health, illness, treatment, and outcomes are perceived.

Findings from explanatory models of ASD in studies conducted in Australia, Ethiopia, India, and Taiwan cannot be generalized to the Filipino American population. Filipinos and Filipino Americans are not from a homogenous group due to cultural influences from the Americans, Spaniards, and Chinese over years of colonization and trade. Moreover, little is understood in terms of how parents manage a child with ASD, as the studies reviewed were limited in the sample studied, as two studies focused on toddlers and school-aged children, while the other study focused on adolescents. Additionally, many studies have focused on the maternal, not paternal perspectives. Management and treatment may differ and evolve over the course of time and developmental levels.

Summary

In summary, ASD exists as a major public health concern in the United States. Explanatory models of ASD are helpful to aid in our understanding of the beliefs and perceptions of Filipino American parental management of care of a child or an adult with ASD across the lifespan. Filipino American traditional health beliefs and perceptions are central around the notion of balance, and help-seeking behaviors are influenced by traditional cultural beliefs and values. Exploring the processes in parental management care for a Filipino child or an adult with ASD is necessary for identifying cultural beliefs, perceptions, attitudes, and practices that may influence seeking treatment and optimizing patient outcomes.

CHAPTER FOUR

METHODS

Research Design

This primarily qualitative study utilized a grounded theory approach to address the research questions (see Appendix A). Initially, study participants completed a self-administered demographic questionnaire and two validated instruments. The questionnaire gathered demographic information on parents and the child or adult with ASD, and the instruments measured the level of acculturation and the level of parental adjustment to childhood illness. Following the surveys, a qualitative approach using grounded theory methodology addressed the research questions (Corbin & Strauss, 2015). The participant responded to a series of open-ended questions to elicit their beliefs and perceptions about ASD and their experiences managing care for a child or an adult with ASD.

Grounded theory involves a process in which the researcher brings data from participants, interactions, observations, and materials to higher levels of abstraction via coding and writing analytical memos (Charmaz, 2014). The data is analyzed through various means, such as sorting and synthesizing, as well as comparing and contrasting (Charmaz, 2014). The goal of grounded theory is the development of "an abstract theoretical understanding" rooted in the lived experiences of the study participants (Charmaz, 2014, p. 4).

Research Questions

The primary research questions addressed in this research study are: (1) What are Filipino American cultural beliefs and perceptions about ASD? and (2) What are the experiences of Filipino American parents managing care for children and adults with ASD?

Specific Aims

The study's specific aims are: (1) to explore Filipino American cultural beliefs and perceptions about ASD; (2) to describe how Filipino American parents manage care for children and adults with ASD; and (3) to generate an explanatory framework on processes involved in Filipino American parental management of care for children and adults with ASD.

Population

The study population was comprised of adult (age 21 years or older) Filipino American parents—mothers and fathers—of a child aged 2 to 17 years diagnosed with ASD or an adult aged 18 years or older diagnosed with ASD and residing in Southern California. Autism spectrum disorder is formally diagnosed after the age of 2 years (CDC, 2020c). Children with ASD disabilities are eligible for services and support through the Individuals with Disabilities Education Act (IDEA) (U.S. Department of Education, n.d.). This statute highlights that early intervention is available for individuals starting at birth through 2 years of age, and that special education and support services are available between ages 3 to 21 years of age through IDEA Part C and IDEA Part B, respectively (U.S. Department of Education, n.d.). Of all the states in the US, California reports the greatest population concentration of Filipinos at 43% (Hoeffel et al., 2012).

Sample

Inclusion criteria for participants include the following: (1) self-identified Filipino American parent (mother or father) of a child aged 2 to 17 years or an adult aged 18 years or older diagnosed with ASD; (2) parental age of 21 years or older; (3) ability to read, write, understand, and speak English; (4) child between ages 2 to 17 years diagnosed with ASD or adult aged 18 years or older; (5) child or adult has been formally diagnosed with ASD by a licensed health care provider; (6) child with ASD resides with a parent; and (7) parent and child or adult with ASD reside in Southern California. Exclusion criteria for participants include the following: (1) parent has been diagnosed with a cognitive impairment; and (2) parent does not have custody of child with ASD.

Recruitment

Recruitment of research participants occurred through two organizations serving ASD, the San Gabriel/Pomona Regional Center (SG/PRC) and North Los Angeles County Regional Center (NLACRC). The State of California has 21 regional centers that coordinates services and provides support for individuals diagnosed with developmental disabilities (California Department of Developmental Services, 2020b). These regional centers track client caseload or consumers by ethnicity, where Filipinos are tracked as a separate group from Asians, but the regional centers do not track the disability by ethnicity. During fiscal year 2018-2019, 2.22% of total consumers in the 21 regional centers in California are of Filipino descent, and 6.8% of total consumers are of Asian descent (California Department of Developmental Services, 2020a). Both SG/PRC and NLACRC are private and nonprofit and work in conjunction with the California Department of Developmental Services (North Los Angeles County Regional Center, 2020a; San Gabriel Pomona Regional Center, 2020b).

SG/PRC has an established Filipino Parent Support Group that provides parents with resources and support for their child with a developmental disability (San Gabriel Pomona Regional Center, 2020a). This group meets monthly and has educational forums about services provided by SG/PRC and social events throughout the year. Likewise, NLACRC also has an established Filipino Support Group that meets monthly to educate consumers about resources for their child with a developmental disability and organizes social events (North Los Angeles County Regional Center, 2020b). During fiscal year 2018-2019, Filipinos comprised 2.46% of total consumers at SG/PRC and 2.41% of total consumers at NLACRC (California Department of Developmental Services, 2020a)

Recruitment letters were disseminated to Filipino families and individuals who receive support through SG/PRC and NLACRC (see Appendix B) and recruitment flyers (see Appendix C) were disseminated during the support group meetings. Additional recruitment strategies involved electronically disseminating recruitment letters and posting flyers to various organizations or sites in Southern California (see Appendices B and C). These organizations and sites include: (1) autism centers; (2) Filipino community groups; (3) autism support groups; (4) Filipino church groups; (5) Filipino markets and restaurants; (6) autism clinics; (7) Filipino nursing organizations; (8) Filipino alumni associations; (9) Filipino community events; and (10) respite care services.

Potential research participants contacted the research Principal Investigator (PI) directly regarding their interest in partaking in the study via telephone or electronic mail. Study eligibility was determined through telephone screening. A screening script guided the 15 to 20 minute eligibility screening process, where information about the research study was provided and callers answered a series of questions on the inclusion and exclusion criteria (see Appendix D). Based on the responses of the potential study participant, the PI determined eligibility for the study. Once determined eligible, the newly recruited participant (only one parent of each child with ASD) was required to sign the consent form and to participate in the study. They were told that participation in the study is voluntary, that healthcare and other services do not depend upon their participation, and that they can refuse to answer any question addressed in the study.

Setting

Data were collected in various settings in Southern California, which were mutually agreed upon by the participant and the PI. The self-administered questionnaires were followed by the qualitative approach to collecting information on ASD. Data collection took place at the participant's home, office space, café, or restaurant. If requested by the PI or participant, a follow-up meeting was scheduled in order to facilitate completion of the questionnaire and/or the grounded theory portion of the data gathering.

Sampling

Following the self-administered questionnaire, the qualitative data collection proceeded via two sampling processes—purposive sampling and theoretical sampling. Purposive sampling was initially be used, where research participants were selected based upon researcher determination of best fit or most representative of the population to be studied (Polit & Beck, 2004). Subsequently, theoretical sampling was employed later as a strategy to drive the data collection process for this study based on data collected from earlier interviews. According to Corbin and Strauss (2015), theoretical sampling is a unique method that involves data collection grounded in themes and concepts elicited from the data. Research participants are the tools in which concepts are unearthed, as their narratives provide events, situations, persons, and places that define concepts (Corbin & Strauss, 2015).

A circular process of data collection and review provided the impetus for theoretical sampling (Corbin & Strauss, 2015). Once the researcher collects data, analysis ensues and questions are generated and explored in additional data collection events (Corbin & Strauss, 2015). As this process repeats, concepts highlighted are well delineated and explicated (Corbin & Strauss, 2015). The point at which no new information can be garnered from the data, known as saturation, determines the final sample size (Corbin & Strauss, 2015; Creswell, 2013). For research studies utilizing grounded theory, it is suggested that attaining saturation would necessitate at least approximately 20 to 30 research participants to ensure generating a sound theory (Charmaz, 2014; Creswell, 2013). For this study, however, saturation was reached at 18 participants.

Ethics

The University of California, Los Angeles (UCLA) South General Institutional Review Board (SGIRB) within the UCLA Office of Research Administration Human Research Protection Program approved the research study via expedited review. This IRB oversees social-behavioral research under the auspices of the Schools of Medicine, Nursing, and Public Health (UCLA Office of Research Administration, 2019). Such research encompasses studies about epidemiology, health outcomes, health services, and human attitudes, behaviors, and beliefs (UCLA Office of Research Administration, 2019). The PI and other research personnel completed all training mandated by UCLA SGIRB prior to IRB approval.

Procedures

Screening Procedure

Study participants signed an informed consent form (see Appendix E) outlining the risks and benefits of participation upon enrollment in the study. The PI verbally reviewed the information sheet with the research participant, and addressed all questions that arose.

Research Risks and Benefits

Minimal risks were involved for participants enrolled in the study. Anticipated risks included an increased awareness of unpleasant or negative feelings and emotions that may upset research participants during the data collection phase. For instance, questions on diagnosis, age at diagnosis, etc., may serve to recall unpleasant or painful memories. In the event that any risk occurred, the PI had a plan to facilitate a "time out" period and/or offer to reschedule the interview. The participant would also be referred to a clinic or counselor if agreeable. If the participant chose to proceed, the PI would continue the interview; otherwise the interview would stop and efforts would be made to restore the session if agreeable to the participant.

Research participants received no direct benefits to participation in the study, however, the information provided is valuable to understanding the personal experiences of Filipino American parents managing care for children and adults with ASD. Information provided to the participant was written and verbal. Participants were also assured that the information they provide to the PI will be secured in a locked filing cabinet and that this information will be confidential and not shared with others. Only the PI and her dissertation chair had access to the data. Reporting proceeded with grouped data so that individuals would not be able to be identified. All data would be destroyed upon completion of the study.

Consent Procedure

Two copies of the informed consent form were signed and dated by the research participant and the PI. One copy was given to the research participant and the other copy was kept in a locked cabinet in a secured office by the PI. Participants were told that they were participating on a voluntary basis, and they may refuse to answer any interview questions or choose to withdraw from the study at any time without fear of denial of services or other care.

Participant Incentive

Research participants received a $30 gift card from Target as an incentive for participating in the study. Target was selected due to the selection of items sold as well as access through in-store or online purchases.

Data Collection

Enrollment

Data collection proceeded through various means: (1) a self-administered questionnaire containing demographic questions (gender, age, etc.), an acculturation instrument, and a parental adjustment to child illness instrument and (2) a personal, open-ended interview to gather beliefs and perspectives about ASD, and experiences managing care for an individual with ASD. Once informed consent was obtained, completion of the questionnaire and the instruments commenced, and lasted approximately 15 to 30 minutes, and the observation and interview lasted approximately 45 minutes to 1.5 hours. Writing utensils (e.g., pens) were provided to complete the paper forms (e.g., informed consent, demographic information questionnaire, acculturation instrument, and parental experience of child illness instrument).

Demographic Questionnaire

The demographic questionnaire was comprised of 54 questions about the participant—mother or father of a child or an adult diagnosed with ASD. Information on the child or with ASD was also collected at this time. Eighteen open and closed-ended questions asked about demographic information of the parent. These questions included the following: date of birth, gender, educational level, occupation, annual household income, first language, nativity, immigration date (if applicable), place of birth, marital status, religious or spiritual affiliation, health insurance, and number of children in the household (including child or adult with ASD), (see Appendix F). Thirty-six additional open and closed-ended questions inquired about demographic information, special education, and health status of the child or adult with ASD. These questions included the following: date of birth, gender, ethnicity, nativity, immigration date (if applicable), place of birth, grade level, Individualized Education Program (IEP) enrollment, type of school or program, age of child or adult when suspected of having a developmental disability, age of child or adult when diagnosed with ASD, special therapy (if applicable), health insurance status, chronic health conditions (if applicable), and special treatments (see Appendix F).

A Short Acculturation Scale for Filipino Americans

The English version of a validated acculturation instrument, A Short Acculturation Scale for Filipino Americans (ASASFA), was used in the study. Adapted from a validated acculturation tool, A Short Acculturation Scale for Hispanics (ASASH), ASASFA measures the level of acculturation in Filipino Americans (dela Cruz, Padilla, & Butts, 1998). Two versions of the tool were developed—one in English and the other in Tagalog—the two national languages in the Philippines (dela Cruz et al., 1998). This tool was based on ASASH due to similar historical contexts and patterns between Hispanics—particularly Mexican Americans—and Filipino Americans, where Spanish influence affected cultural norms and values during colonization (dela Cruz et al., 1998). Internal consistency for this instrument produced a Cronbach's alpha coefficient score of 0.85 (dela Cruz et al., 2000). Additionally, congruent results as ASASH were noted from principal components factor analysis with varimax rotation: (1) preferred language use in social situations (e.g., home, friends, work); (2) preferred language use in media (e.g., radio, television); and (3) ethnic social relation preference (dela Cruz et al., 2000). Prior to ASASFA, acculturation instruments were nonexistent for Filipino Americans (dela Cruz et al., 1998), who comprise the second-largest Asian group in the United States (Hoeffel et al., 2012).

Administration details. The ASASFA scale is a 12-item self-administered instrument that Filipino Americans complete using pen and paper (dela Cruz, Padilla, & Agustin, 2000; see Appendix G). This instrument is comprised of three subscales that examines various aspects of acculturation: (1) preferred language use in social situations (e.g., home, friends, work); (2) preferred language use in media (e.g., radio, television); and (3) ethnic social relation preference (dela Cruz et al., 2000). The first subscale includes 5 items that describe language use of the individual: (1) general reading and speaking; (2) childhood language; (3) home language; (4) thinking; (5) speaking to friends (dela Cruz et al., 2000). The second subscale consists of 3 items that describe media language preference: (1) watching television; (2) listening to the radio; and (3) media preference language (dela Cruz et al., 2000). The third subscale incorporates 4 items that consists of ethnic social relation preference: (1) close friends; (2) social gatherings or parties; (3) visitors or individuals visiting the individual; and (4) children's friends (dela Cruz et al., 2000).

For the first two subscales—language use and media preference—items on the subscale are rated using a Likert scale, where 1 = only Philippine language(s), 2 = more Philippine language(s) than English, 3 = both equally, 4 = more English than Philippine language(s), and 5 = only English (dela Cruz et al., 2000). For the last subscale—ethnic social relation preference—items on the subscale are also rated using a Likert scale, where 1 = all Filipinos, 2 = more Filipinos than Americans, 3 = about half and half, 4 = more Americans than Filipinos, and 5 = all Americans (dela Cruz et al., 2000). According to the authors, "Philippine language(s)" (p. 197) include Filipino dialects, such as Tagalog, Visayan, Ilocano, etc. (dela Cruz et al., 2000).

Scoring method. Upon the completion of ASASFA, instrument scoring results from the summation of all of the items in a subscale and then dividing it by the number of the items in the subscale (dela Cruz et al., 1998; dela Cruz et al., 2000). This average score denotes preference for Philippine language(s)—lower number—or English language—higher number—or language use and media preference, and preference for social interactions with Filipinos—lower number—

or Americans—higher number (dela Cruz et al., 1998; dela Cruz et al., 2000). Moreover, taking the summation of all of scores from the 12 items and dividing it by the total number of items, 12, provides a total mean acculturation score, where a lower score indicates the individual is more Filipino and a higher score indicates the individual is more American (dela Cruz et al., 1998; dela Cruz et al., 2000).

Parent Experience of Child Illness

The short form of the Parent Experience of Child Illness (PECI) was also used in this study. This validated instrument measures levels of parent adjustment when caring for a chronically ill child (Bonner et al., 2006). This tool was developed to address the need for a more thorough understanding of parent adjustment in the context of both positive aspects, such as emotional resources that tap into parents' favorable strengths and negative implications including guilt, worry, sorrow, anger, and uncertainty (Bonner et al., 2006). Development of the scale warranted an interdisciplinary approach comprised of the following health care professionals—a pediatric neuro-oncologist, an oncology nurse practitioner, two pediatric psychologists, a chaplain, and a social worker (Bonner et al., 2006). The team initially developed 60 items that encompassed matters faced with parenting a child with a chronic illness, and through team discussion, decreased the measure to 36 items (Bonner et al., 2006). A group of five mothers and one father of pediatric oncology patients (three patients in remission and three patients in treatment), reviewed the items, and reduced the measure to 25 items (Bonner et al., 2006).

This instrument, along with the Brief Symptom Inventory (BSI), a 59-item instrument measuring psychological symptoms such as anxiety and depression; Caregiver Strain Questionnaire (CGSQ), a 21-item instrument measuring difficulties in parenting role), Impact on

Family Scale (IFS), a 33-item item instrument measuring how illness influences family functioning, and Impact on Event Scale (IES), a 15-item instrument that measures presence of post-traumatic stress disorder symptoms from the prior week, was then administered to 148 primary caregivers of children with brain tumors (Bonner et al., 2006).

Exploratory factor analysis generated four factors: (1) guilt and worry (e.g., guilt stemming from responsibility from child's illness or worry about the child's well-being across time); (2) unresolved sorrow and anger (e.g., envy of others raising healthy children); (3) long-term uncertainty (e.g., thoughts about the uncertain future of their child); and (4) emotional resources (e.g., confidence in addressing challenges that may arise due to their child's condition) (Bonner et al., 2006). Internal consistency yielded Cronbach's alpha coefficient scores for each factor or subscale: (1) guilt and worry $\alpha = 0.89$; (2) unresolved sorrow and anger $\alpha = 0.86$; (3) long-term uncertainty $\alpha = 0.80$; and (4) emotional resources $\alpha = 0.72$. Moreover, Pearson's correlations were used to determine construct validity through examining PECI scores with each of the four instruments administered (BSI, CGSQ, IFS, and IES) and positive correlations were found for the distress subscales for PECI (guilt and worry, unresolved sorrow and anger, and long-term uncertainty), and negative correlations were found for emotional resources (Bonner et al., 2006).

Administration details. The PECI measure is a 25-item self-administered instrument that parents of a child with a chronic illness complete with pen and paper (Bonner et al., 2006; see Appendix H). This measure is comprised of four subscales that examine the parent experience of adjustment in caring for a child diagnosed with a chronic illness: (1) guilt and worry; (2) unresolved sorrow and anger; (3) long-term uncertainty; and (4) emotional resources (Bonner et al., 2006). The guilt and worry subscale is comprised of 11 items, where 2 items are found on other subscales (Bonner et al., 2006). The unresolved sorrow and anger subscale is comprised of 8 items, where 3 items are found on other subscales (Bonner et al., 2006). The long-term uncertainty subscale is comprised of 5 items, where 1 item is found on another subscale (Bonner et al., 2006). The emotional resources subscale is comprised of 5 items, where 2 items are found on other subscales (Bonner et al., 2006). The individual is instructed to rate each item on the measure using a Likert scale, where 0 = never, 1 = rarely, 2 = sometimes, 3 = often, and 4 = always, based on their experiences over the past month (Bonner et al., 2006).

Scoring method. Upon the completion of PECI, instrument scoring commences through calculating a score for each subscale (Bonner et al., 2006). The summation of scores from each subscale is found, and then divided by the total number items in the subscale (Bonner et al., 2006). The guilt worry subscale is comprised of items 3, 6, 7, 10, 13, 14, 16, 20, 22, 24, and 25, where the code is reversed for item 14 (Bonner et al., 2006). The unresolved sorrow and anger subscale is comprised of items 1, 2, 12, 15, 17, 19, 21, and 25, where the code is reversed for item 2 (Bonner et al., 2006). The long-term uncertainty subscale is comprised of items 1, 4, 8, 9, and 18 (Bonner et al., 2006). The emotional resources subscale is comprised of items 2, 5, 11, 14, and 23 (Bonner et al., 2006). Based on the results from psychometric testing, the mean scores and standard deviations were found for the following subscales: (1) guilt and worry (mean = 1.72, standard deviation = 0.773); (2) unresolved sorrow and anger (mean = 1.51, standard deviation = 0.820); (3) long-term uncertainty (mean = 1.97, standard deviation = 0.867); and (4) emotional resources (mean = 2.70; standard deviation = 0.658) (Bonner et al., 2006).

Personal Interview

Personal interviews conducted with participants employed a semi-structured interview guide. This guide is two-fold, where the former addresses parental beliefs and perceptions about

ASD, and the latter addresses management of ASD. Semi-structured interviews are often utilized in grounded theory, where "overview questions" are posed, and later followed with probes to encourage research participants to share their experiences (Wuest, 2012, p. 236). Open-ended interview questions were developed to foster exploration, not interrogation, of the research topic (Charmaz, 2014). This open-ended format allowed the research participant to elaborate and reflect on their responses. The interviews were digitally recorded using two separate electronic devices to ensure a backup is available should a file become corrupted.

Beliefs and perceptions about ASD. To capture Filipino American parental beliefs and perceptions about ASD, eight open-ended questions adapted from Kleinman's explanatory model of illness were posed to research participants (see Appendix I). These questions addressed various following topics: (1) Could you tell me what you think has caused your child's autism spectrum disorder? (2) Why do you think your child's autism spectrum disorder started when it did? (3) Could you tell me what you think the autism spectrum disorder does to your child? Could you tell me how severe autism spectrum disorder is for your child? (4) Could you tell me if the condition will have a long or short course? (5) Could you tell me about the type of treatment that your child should receive? (6) Could you tell me about the most important results you hope to receive from your child's treatment? (7) Could you tell me about the chief problems that your child's autism spectrum disorder has caused for them? and (8) Could you tell me about what your fear most about your child's autism spectrum disorder? (Kleinman et al., 1978).

Management of ASD. A series of open-ended questions about management of ASD will be posed to the research participants (see Appendix I). These questions include a variety of topics that relate to the daily management of the developmental disability. These topics include: (1) describing what the parent knows about ASD; (2) recalling the child's or adult's diagnosis of

ASD; (3) describing a typical day for the child or adult with ASD; (4) describing a typical appointment with the child's or adult's primary care provider; (5) recounting individuals who were helpful to the parent caring for the child or adult with ASD; (6) recounting individuals who were not helpful to the parent caring for the child or adult with ASD; (7) describing thoughts about how Filipino Americans view ASD; (8) recalling how religious or spiritual beliefs affect perception about ASD; (9) reflecting upon how ASD affects the future; (10) describing what it means to be a parent of a child or adult with ASD; and (11) sharing any other issues, topics, or experiences with ASD not previously mentioned in the interview.

Data Management

The management of all data collected during the course of the study entailed the process of participant identification, data collection, transporting, storage, and security of information and data prior to data analysis.

Participant Identification

Each participant recruited and properly consented into the study received a unique identifying number. Participant names were not recorded on questionnaires or within the audio recordings in order to maintain participant confidentiality. Participants were identified by a unique number that was retained for both the questionnaire and the personal interview recording.

Transporting and Securing Collected Data

Data was collected in two formats: questionnaires and audio recordings. Once questionnaires were completed, the PI placed them in envelopes, which were sealed and transported immediately to the research office to be secured under lock and key prior to data analysis. Pseudonyms were used in place of participant names, and all participant identifiers were redacted from the questionnaire form. Likewise, each interview was audio recorded.

Audio recordings were labeled by date and interview number. The PI took care not to identify the participant by name. Audio recordings were transcribed verbatim and care was taken to include only the interview number, as names were not used or identified during the interview. Once transcribed, the recordings were destroyed.

Confidentiality

Confidentiality of the research participants was upheld through protecting personally identifying identification and securing collected data. Due to the nature of qualitative data collection through observations and interviews, pseudonyms were utilized to maintain anonymity of information shared by research participants, such as actual names of individuals and locations (Corbin & Strauss, 2015). However, the research participant may raise sensitive topics during the interview, and disclosure of any abuse to self or others, harm to self or others, or suicidal ideation or plan warrants a break in confidentiality. In such an event, the PI devised a plan for appropriate referrals to resources and services to address such issues.

All of the data collected were kept in locked file cabinets in a secure office. Research personnel, such as the principal investigator and dissertation committee members, were able to access the data. Each research participant was assigned a unique identification number linking their informed consent, demographic information, acculturation instrument, audiotaped interview, interview transcript, and field notes to ensure confidentiality. A document with this information—the participant and the unique identification number—was compiled and secured in a separate file cabinet from the collected data. Only the PI and associated research personnel had access to this document.

Electronic information, such as the audio files of the interviews, as well as sociodemographic data collected from the demographic questionnaire and data collected from the acculturation instrument and parent experience of child illness instrument, were password protected, and saved on a computer, also password protected, which only the PI has access to. The data will be saved until 5 years after the research study has been completed. At that point, the information will be destroyed through shredding paper documents and deleting electronic files.

Data Analysis

Demographic information and acculturation level collected from the questionnaires were analyzed through descriptive statistics were reported as frequencies, means and ranges. PECI scores were used to triangulate findings from the personal interview. Each interview was transcribed verbatim prior to data analysis. Data analysis commenced with coding processes based in grounded theory methodology. The constant comparative method drives data analysis supported by inductive processes (Charmaz, 2014). This method continuously compares data to highlight similarities and differences, where data evolves in abstraction from raw data to categories, from category to concepts, and eventually from concepts to theory (Charmaz, 2014; Corbin & Strauss, 2015).

Coding provides the process in which the data will be raised to higher levels of abstraction (Charmaz, 2014). First, initial coding began with asking what the data is about, yet refraining from placing interpretation or meaning on the data (Charmaz, 2014). Next, focused coding synthesized frequent and significant codes elicited from initial coding as a basis for forming categories (Charmaz, 2014). Subsequently, axial coding further examined categories through enumerating dimensions and properties (Charmaz, 2014). Last, theoretical coding identified possible relationships amongst the categories for theory development (Charmaz, 2014; see Appendix J).

Other tools were used in data analysis. Memos, or analytic notes, captured ideas, compared data, and formulated questions (Charmaz, 2014). Diagrams served as a visual representation of data and/or ideas, where links, or relationships, between categories were analyzed and demonstrated (Charmaz, 2014). Field notes documented observations during the in- person interview (Corbin & Strauss, 2015; see Appendix K). Reflexive journals explored and reflected upon the researcher's assumptions and biases, as reflexivity is based on the awareness that responses and emotions may influence data analysis and interpretation (Charmaz, 2014; Corbin & Strauss, 2015).

Rigor

Rigor of the research study was established through trustworthiness. According to Lincoln and Guba (1985), trustworthiness captures the degree in which the researcher can assert that research findings and conclusions are plausible. Four criteria for establishing trustworthiness in qualitative research are outlined: (1) confirmability; (2) credibility; (3) dependability; and (4) transferability (Lincoln & Guba, 1985). In this study, both confirmability and credibility were utilized to demonstrate rigor. Confirmability involves the extent to which research findings are rooted through both the research questions and participant responses, and not through the viewpoints, motives, interests, and biases of the investigator (Lincoln & Guba, 1985). Reflexive journaling throughout the research process allowed the researcher to reflect upon and increase personal awareness about biases, assumptions, and perspectives (Corbin & Strauss, 2015; Shenton, 2004). Credibility accounts for certainty in the "truth" (p. 290) of findings derived from participant responses to the research questions (Lincoln & Guba, 1985). In this study, triangulation, eliciting various data sources and methods, such as observations, interviews, and questionnaires, to establish corroboration and further understand interpretations and findings, were used to establish credibility (Lincoln & Guba, 1985).

Summary

The use of a qualitative approach to gather and analyze data in this study provided valuable information on the lived experiences of the Filipino American parent of a child or an adult with ASD. The questionnaires gathered demographic information about the participant and the child or adult with ASD. Information on parental acculturation, parental adjustment to child illness, and ASD beliefs and perceptions were collected and provided much needed data to better understand the status of the parent. Using qualitative methods in grounded theory to address the research questions of the study provided information that resulted in the development of an explanatory framework about Filipino American parental management of care for children and adults with ASD. This provided a wide range of information about the beliefs and perceptions about ASD in the Filipino Americans.

CHAPTER FIVE

RESULTS

Study Overview

This qualitative study focuses on Filipino American cultural beliefs and perceptions about ASD and describes the experiences of Filipino American parents managing care for children and adults with ASD. The specific aims of the study are: (1) to explore Filipino American cultural beliefs and perceptions about ASD; (2) to describe how Filipino American parents manage care for children and adults with ASD; and (3) to generate an explanatory framework on processes involved in Filipino American parental management of care for children and adults with ASD.

Participant Characteristics

Filipino American Parents of Children and Adults with ASD

Eighteen Filipino American parents of a child or an adult with ASD participated in the research study (see Table 1). Fourteen parents (77.8%) were mothers and four parents (22.2%) were fathers. The average age of the participants was 49 years, where the youngest participant was a 35-year-old mother and the oldest participant was a 70-year-old father. The majority of the participants were married (83.3%), while the remaining participants were single (5.6%), divorced (5.6%), or widowed (5.6%). Most of the participants engaged in religious or spiritual practice—83.3% were Catholic, 5.6% were Protestant, and 5.6% were non-denominational. One participant (5.6%) was agnostic. All parents were covered by health insurance—15 parents had private insurance and 3 parents had public insurance. Over half of the parents (55.6%) attended a parent support group for their child with ASD. The average PECI subscales scores for the Filipino American parents were 2.045 for guilt and worry, 1.799 for unresolved sorrow and anger, 2.567 for long-term uncertainty, and 2.756 for emotional resources, where 0 = never, 1 = rarely, 2 = sometimes, 3 = often, and 4 = always, based on their experiences over the past month (Bonner et al., 2006).

All of the participants held a college degree—14 participants earned a bachelor's degree, 2 earned an associate's degree, 1 earned a master's degree, and 1 earned a doctorate degree. Over half of the participants worked full-time while nearly one-fourth of the participants worked part-time. The remaining participants (16.7%) were retired or a homemaker. Half of the participants (50%) worked in healthcare across various fields, such as nursing and respiratory therapy, while the remainder of the participants currently or have worked in the following industries: education (5.6%), finance (5.6%), government/public service (5.6%), hospitality/tourism (5.6%), office/administrative (11.1%), real estate (5.6%), and retail/sales (11.1%). The median monthly household income was $8,000.

Over half of the participants (66.7%) were born in the Philippines, over one-fourth of the participants (27.8%) were born in the United States, and one participant (5.6%) was born in Guam. The first language of these participants was mostly Filipino dialects—Tagalog (44.4%), Visaya (5.6%), and Hiligayon (5.6%). English was the first language for 44.4% of the participants. At home, over half of the parents spoke only English (55.6%), nearly one-fourth of the parents spoke only Tagalog (22.2%), and the remaining parents were spoke both English and Tagalog (16.7%) or English, Hiligayon, and Tagalog (5.6%). Based on the ASASFA, The average total acculturation score was 3.495, preference for Philippine language(s) or English language was 3.533, preference for language use and media preference was 4.463, and preference for social relation with Filipinos or Americans was 2.722, where lower scores on a scale from 1 to 5 indicate a preference for Philippine language(s) or social relation with Filipinos and a higher score indicates a preference for English language or social relation with Americans (dela Cruz et al., 1998; dela Cruz et al., 2000).

Filipino American Children and Adults with ASD

Eighteen Filipino American individuals diagnosed with ASD were represented in this study. Nine participants (50%) were between the ages of 2 and 17 years old, and the remaining 50% were over 21 years of age. The majority of these individuals were male (77.8%) and the remaining individuals were female (22.2%). Nearly two-thirds of these individuals were Filipino/Filipino Americans. Three children with ASD were Filipino/Vietnamese American, 1 child with ASD was Filipino/Caucasian, and 1 adult with ASD was Filipino/African American. Sixteen of these individuals (88.9%) were born in the United States and two (11.1%) were born in the Philippines. The majority of these individuals was enrolled in school or partook in a transition or day program.

Parents of these individuals rated ASD severity as the following—mild (38.9%), moderate (38.9%), severe (11.1%), mild to moderate (5.6%), and starting off as severe then became moderate (5.6%). Sixteen individuals received services from the regional center. All participants received therapy for ASD, which included one or more of the following—physical therapy (5 participants), speech therapy (16 participants), occupational therapy (10 participants), and behavioral therapy (4 participants). Over half of these individuals (55.6%) experienced chronic or mental health issues, including anxiety, asthma, atrial septum defect, allergies, bruxism, constipation, Down syndrome, dystonia, hematuria, hyperlipidemia, hypothyroidism, movement disorder, myoclonus, Phelan-McDermid syndrome, portal hypertension, seizures, spasticity, trichotillomania, and ventricular septal defect. Over half of these individuals (55.6%) were covered by a combination of public and private insurance, while one third (33.3%) were only covered by public insurance—13 individuals with Medicaid (Medi-Cal) and 3 individuals with Medicare—and a minority only covered by private insurance—2 individuals.

Half of these individuals (50%) take medication and/or vitamins to address chronic or mental health issues. These include prescription and over-the-counter medications—albuterol sulfate (Ventolin HFA), atorvastatin, baclofen, beclomethasone dipropionate HFA (QVAR), buspirone, cannabidiol oil (THC free), clonazepam, diphenhydramine (Benadryl), divalproex sodium, docusate sodium (Colace), fluticasone propionate (Flonase), lamotrigine, loratadine (Claritin), lorazepam (Ativan), melatonin, montelukast (Singulair), multivitamin, polyethylene glycol 3350 (Miralax), prebiotic, probiotic, quetiapine (Seroquel), serotonin, simvastatin, trihexyphenidyl (Artane), vitamin B12, and vitamin C.

Seventeen individuals with ASD were able to communicate with others verbally using English, Tagalog, and/or Vietnamese, while communicated non-verbally using American Sign Language or augmentative and alternative communication (e.g., pictures). The majority of these individuals (88.9%) used interventions or treatments to alleviate the symptoms of ASD, including applied behavioral analysis (77.8%), complementary and alternative medicine (5.6%), dietary supplements (11.1%), Early Start Denver Model (22.2%), floortime (16.7%), relationship development integration (11.1%), and sensory integration (11.1%). Ninety-four percent of parents necessitated additional help to care for their child with ASD through a babysitter (5.6%), family members (44.4%), child care (5.6%), day care (5.6%), and respite care (55.6%).

Specific Aim 1: Filipino American Cultural Beliefs and Perceptions about ASD

Filipino American cultural beliefs and perceptions about ASD were elicited through the use of Kleinman's Explanatory Model of Illness using open-ended questions that addressed the following topics: (1) etiology; (2) symptom onset; (3) severity; (4) illness trajectory; and (5) treatment modalities.

Etiology

The etiology, or cause of ASD, was comprised of an array of elements, such as environmental factors, medical conditions, pharmaceutical products, prenatal events, genetic history, and/or superstitious beliefs. Each parent reflected upon past events that led up to their child's diagnosis of ASD.

Environmental factors. Nida, a 40-year-old mother in healthcare, attributed her daughter to have ASD due to the environment that she was in while pregnant. She provided an introspective description about exposure to various substances at this time:

> I really think it could have been I- environmental. Um, when I was pregnant with her, like in the beginning, and then throughout, we were flying back and forth to Seattle all the time. And I noticed I was always…and I was really nauseous so that was like… I mean, I had very bad morning sickness for the first few months. Um, like it just seemed like I was exposed to a lot of like, I guess, like you know, like outdoor substances. You know. Like, a lot of my friends still smoke, uh, you know, and then his parents live right near the airport. And next to the freeway. So, like, I literally thought, like, it was just everything that I was around. I was really exposed to a lot.

Nida felt that the combination of such environmental factors, such as tobacco smoke, airport pollution, and automobile pollution were liked to her nausea, which subsequently affected her unborn child. Her reflection of this prenatal period identified these as possible causes for her daughter to ultimately have an ASD diagnosis.

Medical conditions. A child's medical condition was also noted to be a causal factor for ASD. One retired 59-year-old mother, Sofia, described her daughter's medical illness to be associated with ASD:

> I'm thinking when the cause of her autism is just because when she was born, um, she didn't eat well and they put her the G-tube. But, but, but after that, we didn't know that at the age of three. Um, she would, she, she bleeds. And we didn't know that, um, she had that, um, portal hy- hypertension. You know, her umbilical, I think the, they put a medicine through umbilical cord and it, that caused her, um, the portal being clog. And then after that, um, when they just find out she was bleeding, they put her into deep sleep to correct that, uh, bleeding inside of the stomach. Uh, those are the vein that erupting inside. So that's, they do that every, almost every six months, sometimes four months until age of 10. So the anesthesia, I believe, is causing her delayedness.

Sofia attributed that ASD was due to a cascade of medical events that led to a developmental delay. She factored in the lack of nutrition her daughter had as an infant, which led to a gastrostomy tube (G-tube) insertion for enteral feedings, and an umbilical catheter for medications, which subsequently clogged her daughter's portal vein and caused portal hypertension and bleeding. The anesthesia further compounded this delay due to the frequency of its administration over a decade.

Another parent, Perlita, a 65-year-old mother in real state, attributed her son's diagnosis to low levels of bilirubin at birth. She recalled how she would introduce her son in social setting using the following:

> So we're always somewhere every weekend. So we bring our whole family and then they'll notice my son, oh, my son. Oh, he's, yeah, he's special. I always felt loved right

> he's special. Um, when he was born, his bilirubin shoot up, his brain got affected, so this is special… "Oh my son has been affected by bilirubin, and so he's developmentally delayed. He's not going to be normal there you go." That's how I say to all of, all of them. So all of my, all of our circle of friends, know from the beginning that he's special.

Perlita introduced her son to her circle of friends and family as being "special" due to his brain being affected by bilirubin. She was aware that others notice her son's behavior, but she used a script to explain any behaviors that may not seem "normal" in social interactions. By doing so, she opened dialogue about ASD.

Pharmaceutical products. Pharmaceutical products may include medications and vaccines. Two parents attributed vaccines as a cause for ASD. One 59-year-old mother, Marisol, working in government/public service, described her son, Jake, twitching after receiving a vaccine:

> At time, he got, like, he was-…the vaccine, and he wa- he got fever and then he was like, twer- twer- and like, what do you call that? Like, go like this. Yeah. Do like that all the time. And I got scared. I don't know what is that, I said, "What's wrong with my baby?" He just- it just started kept going like that, like, "What's wrong?" Yeah. I was scared, yeah, like… So I kept holding him like, "Come, stop, stop moving." Like, yeah. And then, it stopped, but I don't know if I'm not there if he's doing that. So, yeah, that's the first notice. And then, his development was…getting, yeah, like, lesser and lesser, yeah.

Marisol felt the twitching, along with the fever, were the first events that triggered her son to experience developmental delays. Another parent, Divina, a 54-year-old working in hospitality/tourism, also recounted that her son, Simon, began to show regression after a routine vaccination:

> Um, three year-, being three years old like that's the time that I found out that, um, he was having a change behavior and sincerity of his hands is start gradually changed, you know, and-, and, um, speaking of, I mean, talking is also stopped just because of for some reason that I didn't know until I realized during the event of, um, three weeks before his birthday, we-, I have take him to the doctor for vaccination and a few hours after that vaccination, he was having a high fever. And within two days, that high fever didn't come down right away, but then he had blisters on his mouth, inside his mouth. And, um, it took him like almost a week to get better, but after that, the, um, I noticed Simon, he was not speaking anymore. He would-, he would only communicate with me through his gesture, uh, and the sound of uh-uh by pointing something that he wants and especially if he likes to drink milk. He would just act like uh-uh. Like that, you know.

Both mothers identified a change in vital signs—a fever—upon administration of the vaccine, but also witnessed major changes in their children, which were regression to their development. Although both children presented with different symptoms—Jake with twitching and Simon with blisters—the initial event began with the vaccine.

Prenatal events. Prenatal events are those that occur during pregnancy. Some parents may allude to events that occurred during the nine months in which their child was developing in utero as causal factors for ASD. A 60-year-old mother, Ligaya, who worked in healthcare, recalled unusual bleeding during her second trimester of pregnancy:

> Because even though I know there's somewhere there that I made- made a mistake. That's why he turned out to be like this. Because I remember when I was six-months pregnant I was bleeding heavily, three times. And many times I asked doctor, "Is there something to do with that that I have a son like this?" What is what the doctor told me?

> No. So I was thinking that maybe there's like the blood. I'm not a doctor. I'm not a nurse. I'm not a professional. Put it this way, I'm not, I'm not in, I'm not the right person to say that. But with my experience as a mom, maybe there's like blood that's really come out from my… Because when I was six-months pregnant… Yes, I think that's what it is. But of course, doctor will say, "Oh, no. That's not- nothing to do with that." But at the back of my mind there's something to contraview the doc.

Ligaya recognized the significance of the heavy bleeding during her pregnancy as a factor that caused her son to have ASD. Despite the physician describing that the bleeding was not the cause for autism, Ligaya strongly felt that this why her son is developmentally delayed. While she acknowledged that she herself is not a health care professional, she relied on her intuition to find meaning in the prenatal bleeding.

Another parent, Crisanto, a 37-year-old father and registered nurse, described a possible cause of ASD brought forth by his family members:

> It's a lot. I mean I don't want to say that it was because my wife was working a lot and because they said that the blood diverted to uh, diverted to her legs and not to the baby. And that's what probably caused it because he have a low birth weight.

Crisanto's wife is also a registered nurse, and her job requires her to stand up for long periods of time. Their family members alluded to her standing up for prolonged periods of time as the event that caused the low birth weight and subsequent developmental delays.

Genetic history. Another causal belief for ASD is genetic history, where there is a family history of individuals on the spectrum or that the individual with ASD has a genetic disorder linked to the developmental disability. Clarissa, a 57-year-old mother in healthcare, described how she was trying to make sense of her daughter's ASD diagnosis through speculating upon plausible causes:

> Yeah. But yeah, it wasn't until we did genetics- testing early on and I was found to carry the gene. And Karen has the same repeats for Fragile X. And my hus-… I told my husband, "This is part of her now."… "This is what she has, but I don't know if it's directly related to what the autism is-…at the time." But then again, I think he kinda was thankful in a way-…that he knew it wasn't him, his fault. It wasn't his gene [laughs]. It wasn't because of him [laughs]. It was because of me [laughs]. Well, with the- with the Fragile X-…um, syn-…with the repeats-… I think that was- that was the time that it was, I guess, more…that I determined that- "Okay, this is what she has, so- this might be the problem." But I wasn't sure because I carry the gene-…and I'm normal. You know what I mean? And then when we saw the geneticist, they says, "Well, it just happens that way."

Clarissa pieced together bits of pieces that she learned from the genetic testing and interpreted the geneticist's reasoning for the association of Fragile X syndrome to ASD. Similarly, Camille, a 42-year-old registered nurse also associated her son's ASD diagnosis to a genetic disorder:

> So initially I really did not have an idea, and uh, after like I think that, somewhere after two and a half or like before he turned three, I had a feeling maybe he was having seizures. So although when we did our seizure study it was negative, but I really thought he had seizures. So I, and I know seizures can be related to or somewhat related and related to autism or just because of the seizures it changes the way that they are. Then later on I found out that he has Phelan-McDermid syndrome which is some type of

> chromosome, genetic chromosome deletion. And with that it has autistic like characteristics- plus seizure components within that disorder.

This causal belief of genetics was rooted through Camille's knowledge from clinical practice. She took proactive measures to have her son taken to a neurologist for seizure evaluation, but also doubted the results and opted to get genetic testing. These results confirmed her thoughts about an association between seizures and ASD.

Stella, 35-year-old parent of Austin who has an office/administrative job, suggested that her son's diagnosis may be due to family history:

> Austin is five. He just turned five the other week. Ah, we didn't really think of anything wrong with him um, around two years old. We did give concerns to our pediatrician that he wasn't speaking that well um, but we also weren't concerned because my son is half Filipino half Vietnam- ah, Vietnamese and I mainly speak English. So he, he had three languages coming, coming through. My dad will watch him a couple of times during the week, so he speaks mainly Filipino, so we didn't think much about it, but he's like, "If you wanna check." 'Cause we also have a nephew on my husband side that is on the spectrum, and he was nonverbal for pretty much like 10 years.

Stella and her husband observed that Austin had speech delays, and initially attributed it to teaching their son three different languages—English, Tagalog, and Vietnamese. However, she did raise concerns about this delay due to family history on her husband's side.

Superstitious beliefs. Some parents draw upon superstitious beliefs as causal factors for ASD. Nestor, a 59-year-old father in healthcare described traditional Filipino health beliefs about ASD rooted in the culture:

> *Mangkukulam* is sometimes uh, or sometimes they get possessed. Yeah, like possessed by a devil. Yeah, or sometimes they think… I don't know about here in the United States, but in the Philippines, you know, sometimes they thought that oh my kids demon possessed or, you know. Instead of uh, going to a medical doctor, they go to the *albularyo* to the quack doctor. And then they…the quack doctor gives them the uh, prayer, the something. And then actually it's not, it's not, you know, it's more of a mental issue, it's more of autistic.

Although Nestor, moved to the United States at 30 years of age, he was able to reflect on views about ASD in the Philippines that were rooted in the culture and the means in which individuals sought treatment from "quack doctors." Another superstitious belief about ASD was embedded in luck. Bernice, a 35-year-old mother in healthcare described how luck played a role in her son's diagnosis:

> Luck. Genetics [laughs]. Um, I really don't know actually. Um, I'm not concerned about it either. Like I don't really care what caused it. It just, it occurred. So, I'm not the type of person that's like, "What if we didn't do this?" I'd… You know, he has it. And so unless there's something we can do now about the underlying cause of it, I try not to think about it so much. Um, I don't… I think that you're, you're born, you're born with autism, and that your brain is just wired differently. And it could've happened in utero, and it's just, it's just luck. Just like kids whose, who have cardiac anomalies, and their heart doesn't form y- y- you know, a certain way. Um, and that's just kind of the luck of the draw. And so, it's not something that develops after birth. It's something that you're born with.

Bernice elaborated on how ASD presented as "the luck of the draw," akin to children who were diagnosed with a congenital anomaly at birth. Such diagnoses that are inborn may not necessarily be preventable, and may occur randomly. She alluded to the diagnosis as something that just happens by chance, which prevented her from worrying about preventative measures that could have possibly taken for her child.

Symptom Onset

Filipino American parents observed changes in their child that led them to suspect an ASD diagnosis. These symptoms were congruent with those noted in DSM-5 criteria, and affected either the child's behavioral patterns, communication patterns, and social interactions. Behavioral symptoms included: (1) aligning toys; (2) hand flapping; (3) hand gestures; (4) pacing back and forth; (5) picky eating; (6) repetitive motions; (7) tantrums, and (8) transition issues. Communication symptoms included: (1) echolalia; (2) lack of words; (3) lack of language; (4) non-verbal communication; (5) speech delay; and (6) speech regression. Social interaction symptoms include: (1) crying for no reason; (2) difficulty focusing; (3) lack of eye contact; (4) lack of focus; (5) lack of interest playing; (6) lack of interest in toys; (7) low social skills; and (8) not responding to name.

Other symptoms noted were those that affected one's senses, intellectual level, motor skills, and overall development. Sensory issues included sensitivity, such as sensitivity to sound. Intellectual levels were affected through pace of learning, such as an individual being a slower learner. Motor skills affected by ASD included: (1) walking delay and (2) walking on toes. Last, development was affected through symptoms such as: (1) delayed potty training; (2) global developmental delay; and (3) not progressing with milestones. The majority of Filipino American parents suspected that their child may have ASD during infancy or toddlerhood, sometime between 8 months to 3 years of age. One 70-year-old father, Orlando, suspected his son, who also has Down syndrome, had ASD at 18 years of age, where symptoms were noted by a special education teacher and relayed to the parent during an Individualized Education Plan (IEP) meeting. Observing these symptoms eventually lead parents to seek further evaluation for their child with licensed health care professionals.

Severity

Filipino American parents described the severity of their child's ASD to be on a continuum, ranging from being less severe to more severe. Seven parents (5 mothers, 2 fathers) described symptoms as mild, 7 parents (5 mothers, 2 fathers) described symptoms as moderate, 2 mothers described symptoms as severe, 1 mother described symptoms as mild to moderate, and 1 mother described symptoms starting off as severe and then becoming moderate. Elisa, a 48-year-old widowed homemaker of a 9-year-old son, Alvin, described her son to have mild autism:

> I just know he's high-functioning, and honestly, if- if we, if he wasn't diagnosed, w- we would just say it's just a behavioral, and that we-…could just live with it, and just accepting it and it's just more of just a parenting style, just telling Alvin, "No," and prompting, he can't do that, "No, no, no."

She described her son as "high-functioning," which means the manifested symptoms are less severe and that her son may function more or less independently.

On the other hand, Efren, a 38-year-old father working in an office/administrative role, described his son as having moderate autism, where he ranked severity with 0 as less severe and 10 as most severe:

> I- I know I'm biased, so in my head, my first thing is to say five. I honestly think he's around seven. I- I honestly don't see a lot of physical, like, like um, developmental

> problems with him. I- I don't know if it's more social-…or more educational, like, inclined that he has these, like, problems with… I don't know, like, where he struggles. I know he could be very smart in certain things. I've seen his reading go from barely able to grasp stuff to, like, when I'm reading he could read the whole thing for me. He's…it-it's weird, where I- I know my bias makes it hard, and I think I should seek out more help for him because I'm completely biased. Like I know that much. Like, I- I- I don't even know how to explain it. Like, I always see him, like, he has his issues and that's why I say, like, my- my gut feel, I say five, like, I see there are issues, but I don't see it where they'll keep him from living a good life. At the same time, I do know that he's…like, his handwriting is not the best. I do know that he's having some social, you know, it's just harder for him to take social cues. So I think honestly it's probably…it's seven, based on just what I don't know, and what help we could, might get him that he could actually end up more well-balanced.

Efren wavered between rating his son a 5 out of 10 and 7 out of 10 on severity based on his personal biases about his son. As a father, he is able to observe his son from his perspective, as well as remove himself from the situation to identify the areas in which his son may struggle due to ASD. In a similar fashion, Camille also reflected upon how and why she rated her son's severity as severe:

> Uh, that's tough. I know, I guess 'cause clinically, I know [laughs] that he is severe. Uh, he would probably good, like, maybe eight or nine? And as he get older, depending on, I just know it, I mean, he could do more than…can, so that's like, maybe like an eight. For right now. I know he's still young so there's still a lot of things that I- I would probably do for him anyway, but, uh, he's pretty severe. Let's see. So the zero would be normal,

> and then at the end, like, really like severe, it would be probably nonverbal, incontinent, doesn't socialize at all, barely any interactions. I mean, he has some interactions. I mean, he can interact or- or he will, um, I mean, he can go to the bathroom by himself. I know he has said a few words. And then he is able to communicate somewhat with like some kind of system. So there is like some things that he does that I know, I guess that wouldn't make him as like a 10.

Camille drew upon her clinical judgment to discern whether her son is rated an 8 out of 10 in severity versus a 10 out of 10 in severity. Although she mentioned that her son is still young at 8 years old, she recognized that he is not independent and may necessitate assistance to limited communication skills. Parents relied on their observations to determine the severity level of their child on the spectrum.

Illness Trajectory

Autism spectrum disorder is a developmental disability without a cure. Despite not having a cure, the majority of Filipino American parents felt like their child will have ASD forever. Nestor described:

> I think that it's gonna last forever. Because I don't think that he'll overcome that There's no medication. Yeah, probably with the help of the ABA he will be…hopefully he can be by himself. That's our goal is for him to be independent. That looks like, you know…because he's already 24, and he still like needs assistance.

As the parent of a child over 21, Nestor had already raised his son through childhood and was able to reflect upon what his son needs to help him become more independent in the future. Similarly, Bernice expressed similar sentiments about the length of time that her son would have autism:

> Forever [laughs]. Um, but he just needs to overcome, he just needs to overcome it. I mean, unfortunately what it means is that he needs to act. He needs to learn to act like everyone else. So, um, society dictates that. So until we build a environment or more inclusion then you know, those, those things aren't gonna really change.

Although Bernice's son is 7 years old, she recognized what her son must do to live with ASD—"overcome" it and "act" on it. She also provided a macroperspective, where a more inclusive environment is needed in society for those to ASD to thrive.

Another parent, Elisa, provided a unique perspective on illness trajectory, stating, "As long as I live, or as long as my son lives." She believed that ASD is something that will always remain a part of both her own life and her son's life. As a parent, she recognized the role she has to help her son grow and develop. Having recently been widowed, her views come from a place of grief and loss. If she passed, ASD would still remain a part of her son, whereas if her son passed, ASD would be a part of her past. Such perspectives on illness trajectory provided an honest realization that ASD affects not only the individual with ASD, but also of their caregivers.

Treatment Modalities

Treatment modalities for Filipino American individuals diagnosed with ASD are varied, which include special treatments or interventions, therapies, dietary supplements, and complementary and alternative medicine. The majority of the children and adults with ASD received a form of therapy—16 received speech therapy, 10 received occupational therapy, 5 received physical therapy, and 3 received behavioral therapy. Similarly, a majority of these individuals also received special interventions—14 received applied behavior analysis (ABA), 3 received floortime, 4 received the early start Denver model (ESDM), 2 received relationship development intervention, and 2 received sensory integration. Dietary supplements included multivitamins, vitamin C, prebiotics, probiotics, and cannabis. Other parents implemented dietary restrictions, such as foods that free from gluten, dairy, and/or preservatives. Complementary and alternative medicine practices also utilized included acupressure, acupuncture, and neurofeedback.

Traditional Filipino treatments of autism may include the use of Catholic prayers and exorcism. Nida described treatments from her grandparents' generation describing exorcism to treat ASD:

> Um, I mean I think I mainly remember hearing like, you know, they have like practices where like, you know, they- they try to like remove some sort of spirit from the kid kind of thing. But that's I think I don't know if I'm associating that with something else, but that's been on of the- one of the beliefs I think I heard.

Similarly, Nestor reflected upon similar practices that have been used in the Philippines for ASD:

> Yeah, sometimes they will pray. And then, they'll pray. Like sometimes the Catholic prayers or sometimes the…like then they will uh, you know, sometimes they will uh, they will whip the- the child or whoever has like possessed. But actually maybe that's anxiety or something. They will whip them. They will like, sometimes they will like, you know, like preach their- their you know, until they have- they have so much pain. Or sometimes they would just pass out [laughs]. Sometimes they will uh, yeah. You know, most of the time maybe it's more of the mental issue. Cause then they will talk about different things. And you know like, the victim would be like small voice like…oh look

> there's uh, he's being possessed by a dwarf or something. So that's how sometimes they thought treating those possessed.

Both of these practices drew upon both religious traditions in hopes to find a cure for ASD.

Specific Aim 2: Filipino American Parental Management of Care for Children and Adults with ASD

Filipino American parents of children and adults with ASD manage care through various strategies that help promote growth and development. ASD is a developmental disability whose manifestation is unique to each individual and parents utilize various measures to manage care throughout various stages of their child's growth over time. These strategies for management of care were derived from categories and associated properties that emerged after initial coding, focused coding, and axial coding as part of grounded theory. Twelve management strategies emerged from the coding and constant comparative processes.

Recognizing Signs and Symptoms of ASD

Recognizing signs and symptoms of ASD is the initial instance in which parents suspect that their child may not be typically developing. This occurs during the initial stages of the child's life, usually during infancy or toddlerhood. Parents are observant of their child's behavior and often interact with others who see the child in various settings, such as family gatherings. This management strategy can be described through two properties: (1) comparing development of child to other children and (2) listening to other individuals' observation of the child.

Comparing development of child to other children. During the early years of a child's life, parents are often eager to learn about normal growth and development patterns and use these patterns as a benchmark to mark their child's progress. Such information can be learned from various sources, such as health care providers, Internet sources, as well as anecdotal information from individuals close to them. Parents may also witness the growth of other children in their own families or through their peer groups and ultimately compare their child to others. Margaux, a 38-year-old mother in healthcare, described:

> Well we noticed that he wasn't progressing like the other kids. He uh…he was nonverbal, he was…he was having hand flapping when he was overly excited. The worst sounds of a buzz clipper drove him nuts. And then, um, and then, uh, he wasn't meeting milestones. That's when I noticed like, something's up. We got to figure out what's going on so, we had a good pediatrician for that.

Margaux's observations of classic signs and symptoms of ASD led her to be concerned about her son's development. She noticed specific behaviors, such as noise sensitivity from the buzz clipper, hand flapping due to over excitement, as well as the inability to verbally communicate. These behaviors were not ones that she saw from other children whom she interacted with. Consequently, she was able to identify her son's pediatrician as the appropriate individual for addressing her concerns.

Listening to other individuals' observation of child. Other individuals often provide parents with their personal observations about the child. Some of these parents may have children of their own or they may work in a profession in which they are trained to care for children, such as a person who works in a pediatric setting. The parent will take notice of this observation and corroborate this information with their observations. Ligaya reflected upon the time when she spoke to her sister and sister-in-law about her son, Joshua:

> And then he doesn't do eye contact. No eye contact. And he's always lining things. You know, that's how I notice. Lining things, you know, toys, and- and sleepers. That's

> how I know this. And then we are watching TV. Whenever he hears like loud music, anything that's loud to him, it bothers him. That's one thing that I notice with Joshua. And then when he was one-year- year-old he started talking, like, "Mama. Dada." And then after- after some other like, um, vaccination or something, uh, he stopped, he stopped talking at age of two- two. He stopped talking. So my sister-in-law, because I'm working at the time, working full-time, and then one of my sister told me, "Ligaya, Joshua is already two. How come he's not, he's not talking yet?" I said, "Yeah, he started." But we have to go to his pediatrician, and because I was working full-time, I didn't see much of what's going on. So she said, "You have to bring him to the specialist, and maybe he will be or maybe if not the special maybe, um, his pediatrician." So I went to the pediatrician.

Although Ligaya already began to recognize signs and symptoms of ASD on her own, such as lack of eye contact, lining up objects, noise sensitivity, and speech regression, the voices of close family members, both her sister and sister-in-law, directly confirmed her observations about Joshua. Her sister-in-law's word choice—"You have to bring him to the specialist…"—highlighted a sense of urgency, which led Ligaya to go to the pediatrician about her son's symptoms.

Seeking Help

Seeking help involves the steps that Filipino American parents take to attain assistance for optimizing the health and development of children and adults with ASD. For many parents, receiving the new diagnosis of ASD is overwhelming, and requires one to search for assistance, in various forms, such as tangible help to assist with the individual with ASD as well as the act of fighting for services the child may need. Two properties describe this management strategy: (1) relying on others and (2) fighting for necessary services.

Relying on others. Management of a child or an adult with ASD requires one to ask other individuals for help, such as family members or professional licensed healthcare providers. This help may range from someone watching the child if the parents has work, school, appointments, or social events to attend. Efren acknowledged the difficulty of caring for his son without his family members' support:

> Honestly, without the help of my aunts and my parents, it'd be very hard to. Um, you know, there was a time where I was going to school and then I…or I was going to work and my girlfriend would stay home and take care of him. Um, sometimes, you know, she had school and my aunts or my parents would take care of him. So, right now, we're at a position where both my parents are retired, my aunt that we're living with has been retired for quite some time. And, you know, they're willing to watch him when he comes home from school, or if either one of us is gone.

In addition to describing how helpful his family members and girlfriend have been watching his son while he was in school or at work, he recognized how lucky he is for such support. Caring for an individual with ASD can be challenging at times due to the presentation of symptoms, such as impaired communication skills or behavioral outbursts. Efren's family members were "willing" to assist with care, which can relieve parents' concerns about securing assistance during busy times.

Fighting for necessary services. Attaining special services for children or adults with ASD may pose challenges due to rules and regulations that are imposed over those overseeing such services. Through speaking with other individuals and obtaining recommendations from professionals, parents become aware of the potential services available to help the individual with ASD. Such services may include 1:1 aides while the child is at school or therapy services which can help with communication or activities of daily living. Camille recounted her experiences with the school district to obtain services for her son:

> It's fighting for like services, their school district isn't always easy. I really wanted a 1:1 for him at school. They weren't going to give it to me. I wanted like more speech. I wanted speech and I wanted OT and they wouldn't give that to me either. And the…all he qualified was for adapted PE. So I mean I guess they said he was too developmentally delayed to, to get those services. Yeah. So it's… I mean I understand 'cause they don't want to pay for something that he's not really going to benefit from and that's why they don't want to do it. But, uh, I think, I usually think those that, that they're, they're the ones who probably need it the most… But it is a money thing, so. But I, I managed. I got an advocate and I got other people to help me with that and so now I have a 1:1 [laughs]. It was a lot of fighting, but well, I fought it. I got what I wanted. I didn't get everything, but I got, I got what was most important. The 1:1. Yeah. Well, I actually, I got a 1:1 with his ABA company. So his ABA company that he's with, an outside agency, they provide the 1:1 at his school. That's what I was really fighting for was to have them provide it for him at school versus the school district providing him a 1:1.

The services that Camille requested—a 1:1 aide at school, speech therapy, and occupational therapy for her son—were ones she strongly felt would benefit her son who is severely impaired by ASD due to his genetic condition. She reflected upon recognizing that funding may be an issue, but also highlighted how others may not see how her son may improve after such therapies even though those who need such services are those severely impacted. Although she was initially denied these services, she had to pick and choose her battles through prioritizing the service that she felt her son needed at a time, a 1:1 aide at school. She enlisted help from an advocate to proceed on this process and succeeded. Efren and Camille provided insightful perspectives about the ease and difficulties associated with seeking outside help or services for their child.

Learning about ASD

Learning about ASD is a management strategy that parents utilize to gain knowledge about the developmental disability. The learning curve for any new diagnoses is quite high during the beginning stages, but also one that is continually present as new treatments become available or the individual exhibits new symptoms to manage. This management strategy is illustrated by two properties: (1) being a proactive learner and (2) gravitating toward others in your shoes.

Being a proactive learner. Upon learning bout the child's diagnosis, parents gain motivation to learn as much as possible about ASD. Although each person utilizes different learning styles to understand new information, some parents draw upon their prior experiences to capture a deeper understanding about the developmental disability. Nida used her educational experiences and healthcare practice as a baseline for understanding ASD:

> Well, initially, I'm a nurse, so, um, I mean, even though my training during nursing school was very vague, I mean it still gave me some sort of idea of mental health. Um, nothing really as far as like, you know, how to screen your child kind of thing. But, just in how to associate with them, and how to communicate with them. Um, I think also having to do a psych rotation at a county hospital when I was going to school there, that it really helped me fine tune it. Um, yeah, that's I…and then pretty much after that was

> based on my own research so, if it wasn't for nursing to really kind of help me, and then my friends that are also, that work for the regional center, and they work with kids. Um, that's really where I based my knowledge from.

Nida used a combination of reflecting upon nursing school, doing research, and interacting with those working at the regional center. Unlike passive learners, Nida took initiative to seek out the information that she needed, whether independently or though others. Crisanto also described a similar style of learning about ASD:

> Ever since my son became one, I learned it. I um, I researched it. I…asked questions with my pediatricians and, um, I've also experienced it with my patients who have autism… It's always the Internet and always like, um, or I always got my resources when I first enrolled Nelson to a ABA therapy and…and that's when I learned a whole lot of autisms. Like th- the lingo, the- the- the different definitions. And different terminologies related to autism.

Also working in healthcare, Crisanto relied upon his clinical practice and skills that he gained from patient education. He was able to witness firsthand how to care for patients with ASD in the hospital setting, but used his time with the pediatrician to clarify things that he may not understand or needed additional information about. Cristanto realized that ASD is its own discipline that required not only caring for the child, but also learning the nuances associated with the field, such as terminology specific to the developmental disability. However, learning about ASD as a non-healthcare provider posed a different experience. Efrem, who works in the office/administrative industry, immersed himself in his son's individualized education programs at school to gain insight about ASD:

> Uh, going to a lot of the IEPs, meeting with his teachers. Uh, the teachers for the school district have been very…really good in helping us, uh, basically figure out what works out best for him, what schools he's going to. The people that have been on, um…in the district have been seeing his progression through his grades. So, we've worked with them now since preschool, going into primary, now into middle school. And that's where I'm finding out most of my information through them. Uh, I probably haven't done as much research online, or in scholarly journals as I should, but a lot of it comes from professionals that I trust, you know, with my son's education. Oh, the same as most parents-…or anybody, like now within this age, just going on the Internet, seeing what resources are available. Kind of seeing, I guess in the beginning was this, like, "How did this happen?" Probably that whole like, "How could this happen?" Um, but, yeah, the Internet probably is a primary source of, you know, finding out more about the spectrum itself.

Learning presents itself on a continuum, where Efrem worked closely with his teachers to learn about how to best cater educational plans for his son. He found the educational system fruitful to his learning due to the confidence he has from those professionally trained to educate his son. Efrem also noted that although he has not immersed himself in learning on his own, he knew that he could rely on scholarly journals or Internet resources to find more information about ASD.

Gravitating toward others in your shoes. Another way for parents to learn about ASD is to reach out to others who understand first-hand how to care for an individual with ASD. Sometimes parents may cautiously seek information about the developmental diagnosis through others who may make them feel safe. Bernice described her emotions about disclosure of her son's diagnosis and how that influenced the sources she gained knowledge from:

> I, um, yeah, I mean right away after diagnosis, I don't think we shared the news. It wasn't something that we were excited to tell people about. It was kind of like something that we were slowly opening up to people about. Um, and again, so the first people we told were people that had experience with kids on the spectrum. And so they were able to share insight as to what therapies they used, and what was effective for them. So, I found that to be helpful. But aside from that, you know, for most people I feel like they just don't understand. So, I really try not to talk about it too much, because the- they don't have a frame of reference. Therefore, they couldn't give me any meaningful feedback [laughs] about you know, what I should be doing as a parent.

Some parents take time to process their child's new diagnosis on their own prior to sharing the diagnosis with others. Bernice was not eager to share the news with her entire social circle, but warmed up to those whose she felt safe with—persons who directly interacted with, worked with, or cared for children on the spectrum. She appreciated those who understood her standpoint as a parent caring for a child with ASD because the information she would receive would be helpful to her situation as opposed to someone who may not completely understand the complexities of managing care.

Organizing Daily Schedules

Organizing daily schedules is a crucial responsibility for parents managing care for a child or an adult with ASD. Those individuals with ASD heavily rely on routine. Any deviation from the routine may cause behavioral outbursts, such as tantrums. Parents rely on these schedules to help their children transition from task to another throughout the day. This management strategy involves two properties: (1) having a daily routine and (2) communicating changes in daily routine.

Having a daily routine. Establishing a daily routine is crucial for parents to ensure that their child with ASD is able to thrive and meet goals each day. Routines are especially important for those who have ASD because it reinforces a sense of stability. Camille detailed her thoughts about how she plans a daily routine to care for her son:

> I- I try to plan my day. I mean, I…when I eliminated a lot of, uh, the other therapies, it-it somewhat simplified. 'Cause we were having issues with the school district at that time, so that's partly why I did that. Now that everything's squared and set, it's a little bit easier. I get the schedule from his ABA company and so I know what days are, and the schedule's pretty much the same and it doesn't change much throughout like the months, so I know that… I know what to expect. And then now school is pretty consistent. A lot of that, it just stays the same. So now, it's a little bit more of a routine for what he does. It's a little bit easier to plan. And then we'll just plan doctor's appointment, so that's- that's the only…then for like other appointments that we have, so doc…when we see the neurologist or other geneticist, or whatever, special things or they-they wanna do… Special things are that they want to do, like lately, they wanted to do an echo, so we saw the cardiologist. It's just a lot of like appointment making… There's more to it, but I don't think it's any different because they still have to see the doctor. They still have to get their shots, their well month check-ups. They still have to see the dentist. They still have to you know, see other things too or they have parent teacher conferences with their teachers, so it's pretty much the same thing, just more of it.

The development of a daily routine is necessary to facilitate steps necessary for the child with ASD to make progress each day. Camille took the initiative to contact the organizations and resources were responsible for providing her son with appropriate treatments, therapies, or interventions. This routine allows for the child to engage in learning activities to promote their development in areas that will help them become more independent. The consistency found in routines gives the child necessary structure on a daily basis.

Communicating changes in daily routine. Routines that are disrupted may be challenging for the individual with ASD. Those with ASD may face difficulty when learning that plans are not executed as expected, and may react through changes in behavior, such as tantrums, meltdowns, or outbursts. To prevent such behavioral patterns, Ligaya effectively communicated to her son about why their trip to the movies was postponed:

> When you promise something to Joshua, you have to do it. Because even though he doesn't talk with Joshua, it stick in his mind. Like when we go, when we go somewhere. That's why- I told him this week we're gonna go see movie. We didn't do. It's a good thing that he doesn't like movie that much [laughs]. If not, he would be mad at me. And then I told him "Okay, Joshua, Mommy's so busy this week. We're going to go next week." I promise him, okay, we're going to go next week. He loves, he loves going to the movie because of the popcorn [laughs]. Popcorn. Food, another one. Again, food.

Through stating to Joshua that she is busy, but will reschedule the movie outing would be postponed to a later date, she gave him reassurance that their activity will still happen. She recognized that this outing would make her son happy, as it involved a food that he enjoyed eating. Moreover, she provided her son with a time frame about when he should expect to see the movie. That way, she prevented him from dwelling upon not being able to see the movie as previously scheduled. The communication style that Ligaya utilized was clear, succinct, and effective.

Integrating into Social Settings

Integrating into social settings is the process in which parents help their child adjust to being with other individuals. These social settings may range from going shopping at a grocery store to attending a birthday party. Such settings all include those that may be planned into their daily routine, such as going to see a primary care provider or receiving therapy. Three properties describe this management strategy: (1) encouraging social interactions; (2) preparing for health care appointments; and (3) promoting safety.

Encouraging social interactions. Encouraging social interactions allows for the individual with ASD to spend time with other persons in a variety of settings. This facilitates building of social and communication skills in various contexts. Bernice described how her son spends much time with extended family members though playing with his cousins:

> We have a very large extended family. So they're always around cousins and aunts and uncles, things like that. He… I mean, they play. They play and- and- and because he's known his cousins all their, all his life, he is definitely a lot more comfortable with conversation with his cousins more so than peers at school. But he is you know, um, still not as verbal as they are. It's a lot more physical play. So, it's more tag. It's more… If they're all watching the same YouTube video, that- that's when they'll co- he'll comment, and talk about what it is that they are doing. If, if- Now, if it's a shared interest, then he definitely will comment a lot more. If it's something he's not interested in, then he'll just kind of like run away, or be like, "Hey, let's play tag." And then they'll just, they'll do that where it's not required for them to talk necessarily.

Communication may pose a challenge to an individual with ASD, as the individual may be limited in their speech or may not fully be able to grasp concepts. Through allowing her son to play with his cousins, Bernice gave her son an opportunity to interact with his peer group and engage in their interests, but also provided him with a means to escape the interaction should he begin to feel uncomfortable in this setting. Experiences such as this fosters the development of picking up social cues as well as the promotion of inclusion.

Preparing for health care appointments. Preparing for health care appointments is a process that requires parents to be mindful of potential emotions that may arise in their child with ASD. The health care setting can be unfamiliar, especially with the various instruments used to obtain vital signs and measurements from the child, such as sphygmomanometer, and the close proximity the provider may have while performing the physical examination. The parent may witness their child feeling anxious in this environment. Sofia described how she prepares her daughter to see her primary care physician:

> Um, to prepare, um, she knows. Because I write down in calendar. But I have to prepare an hour before. I have to dress her up an hour before-…to help her and then get ready. Because if, if, if she were up that she doesn't like to go, I'm gonna give her, um, at least I have a half an hour window. Where actually I'm making it two hours before…it were an hour, just to make a window to prepare. If she's gonna go with no complaint, then we go. But most of the time, she take time to, to stay before we go to an appointment. Like earlier we left… Her appointment is 1:15. We left 11:00. 11:00. Uh, no, actually 10:30 because I went to post office. And then the reason why I like 11:00, I have to drive thru to McDonald to get her food. And I'm kind of like making her, giving her, um, happiness first. Like, like I have to buy the, the cheeseburger, plain cheeseburger and, and while I driving she's eating.

Happiness is central to the care that Sofia provided to her daughter with moderate ASD. She planned ahead through ensuring the appointment is clearly marked on the calendar so that everyone in the household is aware of the day. Through integrating a buffer of time, Sonia prepared for any unforeseen situations, such as her daughter having a tantrum prior to the appointment. Stopping for food that her daughter enjoys also made the experience a positive one, where her daughter can associate going to an appointment with McDonalds, a safe space for her. Perlita also used preparation for her son, Samuel, who has mild ASD, prior to his health care appointments:

> Um, I would like to say that he, that I can calm him down. Like I talked to him and I tell him how it's going to be like, and what to expect, but that for him it's better if he's not really that afraid and, and then the more he tense, the more it's going to be hard and don't tense, just relax. So I'd like but, I don't know but, hopefully it calms him down but I still don't know if it calms him down. But that's how I prepare, and I always tell him what's going to be like, I don't shi-, shield him from whatever he will, so that way he'll not, he will know what to expect.

Contrary to Sofia, Perlita used a direct communication approach to prepare her son for his health care appointments. She verbally explained what he would be expecting during the appointment and ways for him to ease his anxiety through remaining calm. She also did not want him to be surprised, so she was clear and straightforward about the appointment. Both Sofia and Perlita are aware that health care appointments may trigger behavioral issues for those with ASD, and preparation is the key to ease them into this social environment.

Promoting safety. Due to the developmental disability, individuals with ASD may not be able to process complex concepts. Safety becomes an issue for this population, and parents are very concerned that their child may not be able to identify and prevent unsafe situations in their home or in their environment. Nestor shared a story about teaching his son how to cross the street safely:

> Yeah, the common sense is, uh, like walking in the street. I would tell him, " Okay, Rex, you know the danger, right when you cross the street? You have to look left and right when there's a car, you know, like come passing by" and he would just look left and right, but give that signal like "why"? You know, you're like, okay, you might get hit. But I'm already warning him that all right, you might get hit by a car. But he would just go left and right and then go straight [laughs].

Crossing the street safely requires one to be aware of their surrounding environment, such as avoiding cars while walking to prevent injury or death. Nestor observed that his son was able to look in both directions as instructed, but was unable to grasp the importance of doing so. He wanted to teach his son skills to navigate the environment so that he could become more independent, but also recognized that his son may need more cues to facilitate this learning that extend beyond simply looking left and right while crossing.

De-escalating Challenging Behavior

De-escalating challenging behavior requires parents to address situations that trigger the individual with ASD to have meltdowns, tantrums, or outbursts. This is important to have in their toolkit, as challenging behavior may arise at any point during the day. There are two properties that illustrate this management strategy: (1) looking for potential triggers and (2) devising strategies to prevent challenging behaviors.

Looking for potential triggers. Most challenging behaviors arise from situations that trigger the individual to become upset or uncomfortable. The individual with ASD may or may not always be able to communicate or express why they became upset. As a result, parents have to reflect upon the context in which their child became upset and identify, such as retracing the events that occurred at that time. Ligaya recapped how she identified changing routine as a trigger for tantrums:

> It's like a guessing game. Like one, as I said, when we went to Walmart that he, that he acted up. We don't know. Suddenly, he just… We used to really go to Walmart. We used to really go to anywhere. This, this for a longest time, he never had that, that tantrums. It, like, surprises me. What does he want? I didn't know, but that day I think we, we wanted to go somewhere. I think we told you we're going to the mall. I think I was guessing. We supposed to go to the mall, but we went up- and we end up going to Walmart. I think that's what- I think I remember now. Because wh- our plan, okay, you asked the plan. Yeah. The routine, okay. Yeah, the routine. The routine is going to the mall, cause- oh, I have, um, I have to pay something in the mall. But I said, "Oh, I can go, I can go there later," but I have something to buy in Walmart. There's this for day. So paying the bills in the, in the mall, Wal- uh, cause at JCPenney, I think I owe something and then I have to pay my bill. I said, "That's not due. Not until two weeks from now." So I could wait. So, but going to the Walmart cause we have to buy something. So we need to go to Walmart first, then going to the mall. I think that's what it triggers. Always, it triggers something. Routine. Number one for autism is routine. Routine is number one. If the routine is not followed? There you go. Tantrums. Problems.

Through analyzing the events of her shopping day, Ligaya identified the tantrum as being caused by her decision to change the order in which she visited stores. Her son was expecting to stop by the stores in a particular order, and when those expectations were not met, he developed a tantrum. She was aware that those with ASD are fixated on the routines, but one minor change may cause new behavioral issues to emerge.

Devising strategies to prevent challenging behaviors. Addressing challenging behaviors associated with ASD requires one to develop unique strategies that can be implement by themselves or others. Sometimes, the development of such strategies requires some trial and error coupled with observation of their child. An example of a challenging behavior includes a child biting their hand. Camille reflected upon how she changed her son's behavior:

> I think the biting, I didn't really think of it much at the beginning, but towards the end, like when it started getting really bad, it was probably like that's when it really was difficult. And then trying to break even from it was hard, 'cause it took a while. And it was difficult for maybe a therapist to figure out why he was biting. And I think that's what was a big struggle. I mean I thought it was just for, you know, escape or, or attention, and, and it pretty much was. So that's… So I told them, me I go, he stops biting in the car 'cause I ignore it 'cause I have no choice [laughs]. I was like, I can't stop him while I'm driving. And then he stops on his own. So I told them like, like, what if you just stopped, you know, and just not intervened? And so then they, they did and then it pretty much worked. So then it, it started to decrease. So when, now that they figured out exactly why he's biting, they were able to manage it better. And that's kind of how that works.

As a mother, Camille is observant about her child's baseline behaviors, so she becomes alarmed when her son's behaviors are out of the norm. She alluded to her suspicions of her son wanting attention or trying to find an "escape," as her son is unable to express his emotions verbally, but relies on American Sign Language and pictures instead. Through her time in the car driving, she witnessed that her son stopped biting his hand and correlated it to herself not intervening. She suggested this to therapist, who then was able to use this strategy to prevent and/or de-escalate this behavior.

Incorporating Self-Care

Incorporating self-care encompasses ways that parents care for themselves while juggling the responsibilities of parenting a child or an adult with ASD. Receiving a diagnosis of ASD changes the worldview of the parent through the grieving the loss of having a “normal” child coupled with finding ways to ensure that their child is loved and supported. Two properties describe this management strategy: (1) finding solace and (2) engaging in meaningful hobbies.

Finding solace. Finding solace is a means for a parent to seek comfort during challenging moments caring for a child with special needs. Solace may come in many forms, and for many Filipino Americans primarily of the Catholic faith, it may come through prayers. Sofia described how she prayed to God to help her get through her day:

> You know, pray, I, I guess when you pray, um, it will help a lot. I guess God is really, really merciful. Because through all of these that I went through on my daughter and my, me, myself somehow why it’s done. I mean, I manage day by day and it’s there. It’s, it’s, uh, the difficult bec- become light and, and somehow it, it um, um, it solve. I mean it’s solved for the day. I know the next day you have, but for the day it’s solve. And then all the painful you feel before, the stress, and, and I notice when you pray, um, it become light. That’s how I, that’s helped my experience. It become light and I guess, I guess, um, like I said, God is so merciful and she’ll give you whatever that you can only handle. She will not give you, um, probably, um… She will not give you a d-, um, a task that you cannot handle. So that’s how I notice when you pray. Yeah.

Sofia is able to describe the positive aspects of prayer when there are difficult times. She reflected on how her problems are resolved through speaking to God and that she feels a release afterward. Her stressors are washed away and she is left feeling lighter inside. This religious practice allowed for her to prioritize her needs at a time where much of her energy is devoted to ensuring her daughter, Noreen, is taken care of.

Engaging in meaningful activities. Engaging in meaningful activities is a way for the parent to engage in interests and hobbies that they enjoy. These activities are ones that that are enjoyable to the parent, but also afford them with an opportunity for growth in various areas of their life, such as cultivating new skills or learning more about themselves. Sofia continued to discuss using the rosary as a form of prayer as well as her other hobbies and interests.

> You know, um, I, I kind of find a way for me. If, if, um, as a parent, let's say I'm really, really stressed about my daughter, what I do is, um, I, I love… Okay first, first thing in the morning, I love to do, um, rosary, and then b- going to bed, I love to do rosary again. And then during the day when Noreen is not here, um, I love to do, uh, planting like, uh, collecting cactuses. I joined a club, uh, and we meet once a month. And, um, more, more it's plant. You know, and then, um, I do go to the nail shop to make my stress, you know, um, help me. That's my hobby.

Multiple activities can be used to meet a parent's need for self-care. While Sofia is religiously devout, she also spent time partaking in a monthly cactus club. Such clubs allowed for her to socialize with others who share the same interests, and provided an opportunity for her to gain knowledge about the cactus plant. Going for beauty rituals, such as getting a manicure and/or pedicure allowed for her to sit down and relax, as others took care of her. Such activities provide parents a way to escape their reality through creating a sense of normalcy.

Worrying about the Future

Worrying about the future involves a fear that parents have as their child with ASD gets older. This concern stems from the uncertainty that emerges when picturing the future of their child. As parents, they have the responsibility of raising their child and protecting them from harm, but they also ponder about who will assume these responsibilities in the future or whether or not their child will be independent one day. Two properties describe this management strategy: (1) expressing concerns about independence and (2) facilitating family dynamics.

Expressing concerns about independence. One of the biggest fears of parents of individuals with ASD is the future. Many individuals with ASD are dependent upon their parents or other caregivers to function daily. Parents are the one who know their child best and guide them across various life stages. Bernice expressed fear about her son's independence if she is no longer around:

> I think… I think what scares me most is how he's gonna be able to function as an adult. What's probably most scariest is that one day I'm gonna die [laughs]. I'm not gonna be able to like control certain aspects of his environment, and, and things like that. So, what concerns me most is how he's gonna be able to function without me, which I, myself need to learn how to allow him to be more independent, because otherwise he'll never get that skillset-…to be more independent as an adult. So that's probably my biggest fear [laughs].

Through recognizing this fear, Bernice recognized that as a parent, she needed to give her son opportunities to become independent. Her maternal instinct was to protect her child from harm through controlling the environment, but she later recognized this as a limitation that prevented her son from growth. She advocated for his independence, but was trying to find a fine balance that allows her son to gain these skills, but also remain safe during the process.

Facilitating family dynamics. Discussing the future care of an individual with ASD often involves those who may potentially resume care for the individual should the parent pass away. This is a sensitive topic for the parent and those involved, as some family members may hold mixed feelings about caring for individual with ASD in the future. Parents may look to their own immediate family, such as siblings of the person with ASD, to take care of their child. Both Ligaya and Marisol shared conversations about her sons caring for their sibling with ASD. Ligaya stated:

> Of course I want the best for my son, because right now I have two sons, but the other one, he's normal, but when I ask him, "Can you help your- your brother in the future?" Uh, "Can you help him when I'm not, I'm not here anymore? I'm gone?" Let's say I'm gone, me and my husband, and he's the only brother. You know, my hus-, my son said, "Mom, I'm not gonna stop living because of my brother." I accept that, of course. I accept that. I'm not gonna give all the burden to him just to take care of Joshua. I'm not. But who else is gonna help him? I think it's only the parents who can help our son. Nobody else. I know he has relatives, aunties, uncles, cousins, friends. But- but parents is the only one who knows our kid, my Joshua.

Likewise, Marisol expressed a similar situation where her son was disinterested about caring for his brother with ASD:

> My son, my eldest son's supposed to. But, for now, that- when I ask him, "Are you gonna take care of Jake when we're- when we'll be…can't function anymore, or what?" Ch- , "No, mom. I have to put him- " Honestly, that's what he said. "I'm gonna put him

> in a facility." So, I said, "What, are you gonna do this to your brother?" "Yeah, 'cause... uh, I can't take care of him."… Yeah. So, they're- they're really…they're not really buddy buddies. Yeah. They respect each other, but they're not really like, you know, friends friends… 'Cause my son, really, he can't accept that his brother is like that. Yeah, he told me that. Yeah. It- it's painful to him, and it's always question even to God, he question, why he has a brother like that. Yeah. That's- maybe that's, he's always…moody, also, like- yeah, the moment, uh, he changed, he used to be like funny, goo- , young kids. But growing up, no more. He changed.

The issue of caregiving responsibilities is placed upon two separate generations—the generation of the Filipino American parent caring for an individual with ASD and the generation of the Filipino American sibling of the individual with ASD. In the Philippines, the collectivist society often brings immediate and extended families to pull together during challenging times, such as raising a child with a chronic illness or disability. However, the American culture is more individualistic, and a clash of values emerges through these interactions, where the typically developed sons each want to live and focus on their own life.

Navigating Cultural Awareness

Navigating cultural awareness involves being attuned to how culture shapes others' beliefs and perceptions about ASD. Culture adds another layer of complexity to the parental management of individuals with ASD the Filipino American community. Furthermore, the generational differences amongst members of this community also affect how the individual with ASD is treated as well as the interventions they receive for care. Two properties describe this management strategy: (1) reflecting upon perception of ASD in Filipino American culture and (2) acknowledging differences between Filipino generations.

Reflecting upon perception of ASD in Filipino American culture. The perception of ASD in the Filipino American community is one that is shamed and stigmatized. Some parents are embarrassed about having a child with special needs, while others fear the child with special needs. Perlita, an active member of a Filipino American parent support group, reflected upon her efforts to recruit Filipino American parents into the support group:

> Um, um, majority of the Filipinos that I've talked to, they were trying to encourage to come and join the support group because they'll learn a lot from the support group, they'll learn a lot with dealing with their children and the services that are out there. But they're ashamed to know, for other people to know that they have a special child. They're ashamed to know, I mean to feel that, that people are going to brand them as, we have a mentally retarded child or you have a Down baby. They don't like that majority. I mean majority people are… Some families attended one and then you'll never see them again. So I, that's… I highly believe that that's the Filipino. Parents are going to tell you, "Stay away from that." But that's the Filipino culture that I know of. Stay away from that 'cause… And some of them, some of the special kids are violent tantrums. So that's why the parents are gonna say, "Okay, stay away from them because they might hurt you because they're not normal." So it was seeking your brain that they're not normal. So even here I can still see other Filipino families with that.

The notion of "rebranding"—or labeling is a part of being stigmatized. Perlita expressed that some parents do not want be labeled as such, and fear being different from mainstream society. She also alludes to negative behaviors that some Filipino and Filipino American parents have towards individuals with ASD who have violent tantrums that may be difficult to control. Such behaviors furthermore ostracize the individual with ASD in the Filipino American community.

Another reflection about the perception of ASD in the Filipino American community involves help-seeking behaviors. Camille shared her thoughts about the types of treatments for ASD in both the American and Filipino cultures:

> As Filipino Americans, I think we're more open to therapy, we're more open to I guess to looking for resources and- and conforming to like what other Americans would do. Uh, I think it's… I- I think we just pretty much be just- just that. We would do probably whatever they would tell us to do. Uh, they have… I guess they have a different perspective. Usually, they're a little bit older. Even if they were younger generation, they might think a little different 'cause they do have autism in the Philippines. I know like one of their famous actors has a childhood autism too. So, you know, they see things a little different now but initially, lot of times, sometimes they'll think that, you know, you could bring 'em to a healer or if you just, I guess it's more…they- they don't…they're more likely to look for different types of ways to- to- to like I guess to try and cure autism.

Acculturation plays a part in how some Filipino American parents seek care for their child with ASD. She delineated between highly acculturated Filipino Americans who were more receptive to Western forms of therapy and treatment versus Filipinos Americans who immigrated from the Philippines, who may look into traditional healers to cure ASD and rely on means that they are familiar with from their home country.

Acknowledging differences between Filipino generations. Generational differences impact how ASD is viewed in the Filipino American community. Aside from the shame and stigma associated with ASD, the illness trajectory of ASD is perceived differently from one generation from the next. There are distinctions made between the "older" generation and the "younger" generation. Emma, a 42-year-old mother in healthcare, illustrated these differences in perceptions of illness trajectory and treatment:

> Um, older generation they're more old school way, like he's gonna outgrow it. Younger generation, they're more open minded, like, "Oh, he needs therapy at an early age because it helps mold them." So younger generation are more well informed-…mainly because of the Internet nowadays and the information that they can get easily whereas the older generation are more old school. They don't use the Internet. So it's just hearsay. Whatever other people say, they hear it and then they think it's okay. If you take somebody, "Oh, he's gonna overcome it." Like, you know, "He's gonna outgrow it," or "He doesn't have it. It doesn't exist, you're just overreacting." It's like one of my co-worker, he's, uh, he's older than me and he's a cop and the… He has kids, but not in the spectrum. He just told me that… I guess I told him that my son had autism, and then what I remember he told me, "People just overreact in this country. There's no such thing as autism," he said.

Such generational differences provide two different modes of understanding ASD in the Filipino American community. Emma recalled the statement by her Filipino American coworker who denied that ASD was an actual condition. The older generation viewed ASD as something temporary, where the individual may outgrow the developmental disability, whereas the younger generation viewed ASD as a permanent state that requires intervention to shape the child's development. These differences in perspectives influence how ASD is understood, evaluated, and treated within the Filipino American community.

Accepting the Diagnosis

Accepting the diagnosis is the turning point in with the parent recognizes that their child's diagnosis will be a permanent fixture in their life. Parents may initially experience a plethora of emotions upon diagnosis, such as denial, grief, or anger, but these feeling subside once they are able to process these feelings. At this point, parents are able to reframe the situation and look into the future. Three properties describe this management strategy: (1) acknowledging a new normal; (2) making adjustments; and (3) finding the silver lining.

Acknowledging a new normal. Parents grapple with loss during their child's diagnosis. This loss stems from not having the "typical" hopes and dreams that one would have for their child, such as career aspirations and life events. Emma reflected upon her grieving process after he son was diagnosed:

> If you need to, if you need to grieve or you need to cry. Once you get, if you initially, if you need to grieve, you need to cry. You're more welcome to do it. Because that's, that's the first step of accepting. But you have to grieve, you have to cry. And then once it sinks in, you stand up, you dry your tears and then see what help you can do to your son. Give him all the treatments, all the therapies he need or all the opportunities that might help him in the future.

The grieving stage is one that Emma encourages for parents as a way to release negative emotions that come with loss. She noted that this process is a part of accepting the diagnosis. While this may take some time, she took a perspective of creating a new normal for her life—one that included how to help her child in the future through treatments and therapies. Although her new normal may include integrating these interventions to facilitate growth and development of her son, her role as a parent is still to help and guide them to prepare for the future.

Making adjustments. Making adjustments involves changing one's current lifestyle to meet the demands of caregiving. Parents may give up their existing lifestyle to ensure their child is cared for. Some parents may quit their full-time jobs to become full-time caregivers, while others may see the effects permeate into their social life, where they are unable to spend time with their family and friends. Nestor described his strategy about maintaining his social life while caring for two children on the spectrum:

> Yes, so my life… I am a- I am a happy go lucky guy. You know, I dream how I… I always have my friends with me all the time. And then when Rex…when they were born, and Rex has autism…so everything changes, you know. Like, so you just have to adjust your life, you know. But it's not, you know, like adjust it to a point that you never lose your friends, because I don't want to lose like any friends or families. So, I adjusted it, and I told them yeah, we have to adapt, you know, to the situation cause I have two kids. So instead of going to their place they now come to my place [laughs]. You know, but you have to have a good life, we have to- you have to also enjoy your life. Don't focus too much on whatever, you know, kids or…you have to really like adjust.

Through effective communication with his friends and family, Nestor successfully found a way to balance caregiving and socializing. As a collectivist culture, Filipino Americans thrive on interpersonal relationships. He recognized that spending time with his friends and family and caring for his two children were his priorities. Social relationships were as important as parenting and he was adamant to be able to engage in both fully. The fear of losing social support gave Nestor the impetus to explain his situation and devise a practical solution for his friends to visit him instead of vice versa. Speaking to his friends about his situation also provided them with his perspective as a Filipino American parent caring for a child with ASD.

Finding the silver lining. Finding the silver lining involves looking at the positive things that may emerge after a life-changing event. This involves looking at the big picture of a situation, such as caring for an individual with ASD, and focusing on hope and wisdom that may emerge when times may get challenging. Perlita described her silver lining from being a parent of a child with ASD:

> It gives you so much patience. Teaches you patience. Yeah. That's the first and foremost. Teaches you to be aware of everybody else around you, aware of everybody else's feelings around you. Um, well, we've always had, um, we've always known how to treat other, other people that are not in the normal level. Not, not, not just mentally, but also like for example, um, LGBT is not, is part of the not normal too at the time. And they're just getting accepted now. But prior to that, um, there was always a sense of um, separateness, and not all people are open or accepting, accepting of how they are, but social media and through the years, everything's just changing. So I guess that's how it is with nowadays as well. People are learning to tolerate or learning to be kind and accepting of people that are not in the same level as they are mentally and otherwise.

Caring for a child with special needs may bring forth a new perspective or worldview. Perlita summed up her silver lining to patience with others, empathy for others, and accepting others. She was aware that the world has socially accepted norms but also has individuals who may not conform to these norms and may be ostracized for being different. Her experiences as a parent of a special needs child taught her about the importance of inclusion and embracing diversity.

Defining Parenting Role

The role of a parent of a child or an adult with ASD is complex because it requires one to balance numerous tasks and responsibilities. This role is also unique from one parent to another because ASD presents itself on a spectrum and some individuals may require more involved therapies or interventions and another child who is less severe on the spectrum. Four properties describe this management strategy: (1) identifying unique roles and responsibilities; (2) being an influential figure; (3) celebrating child's progress; and (4) being present with child.

Identifying unique roles and responsibilities. Responsibilities involved with caring for an individual with ASD may range from assisting with activities of daily living to reinforcing new knowledge learned from school. These responsibilities may be shared with a partner or some parents make take ownership to complete these responsibilities. Elisa described the changes in her responsibilities caring for her son after her husband passed away:

> When my husband needs s- support, I fill in. So, um, so we have lots of roles. Now when my husband passed away, um, gosh, I had to, I had to piggyback all the roles that my husband did, so that- that I could be one person, one team, and so right now, going back to the vain or the façade, in order for me to feel like I have my life put together, I need to feel like on the outside, I need to look like I'm put together, because if I don't present myself how I truly feel on the inside, then I feel like I can't conquer the world. Does that make sense? So, my role? I have no choice. I am not given a choice, I gotta do what I have to do, I have to do everything.

The responsibilities that Elisa had while her husband was alive were shared between them. She drew upon no longer having a unified team to help care for her son, and unexpectedly having to undertake roles and responsibilities that her husband had on top of her own. She grappled with the sense of loss along with the pressure of being able to "conquer the world." This situation illustrates that a parent may not only be solely a mother or a father, but can be both should a life event force them to absorb their partner's parental role in addition to theirs. Similarly, Sofia described her burden of juggling multiple roles and responsibilities while her husband was focused on working to financially support their family:

> My role, not only a parent's, you'll be like a teacher too. And not only that, you'll be like a therapy too, therapist, um, caregiver. That's your role model, you know. Not only a parent's, you'll like be a teacher, a therapist. Because you're dealing everything like, like a teacher or like a therapist. Once, um, you went through your appoint- to your appointment, once it's done, um, you, you, you deal, you do that too at home and you, you're doing it for her. So it's kind of you're copying the therapists. Like the speech therapist, uh, whatever you learned from her, from the speech therapist, you, you will deal that to your child. So, um, that's my, the, the role as a parents. And her dad, um, my daughter's dad, just keep working, just, you know, working, working to make money to pay for those therapies. So, that's how we do. I, I, as a mother, I do a lot of work than my husband. Because I stay home and I'm not working. I, I do care for her and, and I'm also a caregiver for her. Caregiver, parent, therapist, speech therapist, um, respite…yeah, kind of like that. You're a nurse also, you know. That's why she, she was improve actually. B-, I mean, compared from when she was a little girl, you know. Because we're, we're kind of like do double, double work for her.

Although Sofia has another parent in their household, she described the increased workload caring for her daughter at home. Her daily roles included teacher, therapist, caregiver, and nurse. She had to transition from one role to another depending on what her daughter needed at the time, such as implementing strategies used in speech therapies to taking her daughter to healthcare appointments. Both Elisa and Sofia are faced with pressures that arise due to the unique needs each of their children have.

Being an influential figure. Being an influential figure empowers the role of the parent of an individual with ASD. The parent is the constant fixture in the individual's life through the day-to-day involvement to promote the growth and development of the child of adult with ASD. Margaux reflected upon her motherhood through her experiences from childhood and nursing school:

> Well, um, well like… What I learn from nursing school, the mother is the one. It's always the mother run…the mothering one that- that- that the child is- is… How do I say…is growing with. So, I think I'm very important. I am the very important role in his life. That's what I think, cause I'm his- I'm his teacher forever. Yeah. So, yeah. That's what I think cause it's like, me growing up. Who's always with me? It was my mom. You know, so…and I know that I'm gonna be with him all the time. Who always has the most influence with me, you know, it's my mom. So that's what I think too. I have the most influence with Isaac.

The role of motherhood is significant for Margaux, as it highlights how she is her son's "teacher forever." She recognized that she influences her son in many ways through interactions with him as well as through the decisions that she makes. Moreover, she viewed her role as mother from a place of strength and empowerment.

Celebrating child's progress. Celebrating progress is a salient role of the parent of a child or an adult with ASD. The developmental disability presents some individuals with delays in reaching milestones, such as learning to talk. When progress or milestones are met, parents become overjoyed because they were able to witness their child achieve a goal that was set. Crisanto described one of his successes as a parent when he taught his son to potty training:

> I think one was when I finally got him potty trained [laughs]. Yeah, like I don't remember how that came along. We'd been trying since he was younger, you know you try to start them off like two or three. Like, he was in preschool and he was still getting help. I don't even remember, like, all of the things we used to do to make that we'd get him to the bathroom in time. We're just like you have to go. Let me know now, we'll bring you to there. I don't remember the exact moment. But when… Because I do know, he had to be potty trained before he went to either first grade or something, or kindergarten I can't remember which. Was kinda of like that's the, that's the base minimum, like, maybe it was first grade. Kindergarten, yeah you can help him a little bit. But first grade he needed to know how to do this himself. And I guess just knowing that he can go by himself. That feels, yeah… In hindsight, it's just kinda like, I don't remember when it was. And I know it's a big step for every child. But this is just one of those things where I was so worried that he couldn't start school properly because he wasn't potty trained. And even though we were trying to teach him, like, you know. Stuff like that, I mean it's small victories, I guess.

Although all parents are faced with the task of teaching potty training, this task may be laden with additional challenges when teaching a child with special needs. Crisanto was very concerned about potty training as an obstacle for his son to enroll in school in a timely manner. Despite the strategies that he and his wife used to get his son to the toilet, in the back of his mind, he feared that his son being incontinent might hinder him from receiving the support and resources that a formal educational environment may provide. Once his son was potty trained, he was grateful that his son was able to start school and recognized that these "small victories" were ones that brought him joy and contentment.

Being present with child. Being present with the child is a role that requires a parent to step away from caregiving responsibilities. This allows the parent and child to establish a bond together and enjoy each other's company. Sometimes the pressures of juggling multiple roles to care for an individual on the spectrum may overshadow the parent-child relationship. Efren described how he bonds with son on a weekend:

> If he's at home, cool, but we're mostly just doing our own thing. Like he's in his room. I'm in my room. I'm watching TV, he's putting on his Kindle. But sometimes I'll just be like, "Just come over here. Like you lie down, and do that. Just lie down with me, and we just watch together." I- It's, kind of like a weird thing, where I try to give him his space, but at the same time assure him that I'm here if he needs me.

Spending quality time together is crucial to nurture the parent-child relationship. Although Efren and his son were engaging in separate activities, he himself watching television while his son using his Kindle, they both were within the same space. He fostered being present for his son even though they may not verbally communicate at times. This was Efren's strategy to give his son the reassurance that as his father, he is available and present for him.

Being an Advocate

Being an advocate is an ongoing process that requires parents to be the voice of the child or adult with ASD. As a developmental disability, ASD affects each individual uniquely, and their ability to live an independent life may be affected due to processing given information and communicating with others. Two properties describe this management strategy: (1) seeking necessary resources and (2) protecting child in social situations.

Seeking necessary services. Seeking necessary services is crucial for ensuring that the individual with ASD receives appropriate care. Health-seeking behaviors differ from one culture to another, and influences how parents navigate obtaining these services. Emma reflects upon the Filipino perspective on seeking health care services:

> For them to be more open-minded. And to be providing from the child and, you know, fight for what you think is right for your son. Because Filipinos they tend to accept what's been told by them. They don't even try to fight for it. Especially with government agencies. They tell you something, it's, "Okay, we're happy with it." You don't really fight for it and you don't even question their decision. Which is one thing, you know, just to go fight in what you believe for. Don't take no for an answer. But do it always, always in a nice way. You don't have to be rude. I think how we were raised when, you know, the way I'm looking at Filipinos they're kind of on the inferiors side. Like whatever people say, you just say, "Yes." We don't use a bargain. We don't even bother questioning their decision. Or maybe because we come from a third world country, we don't see any free programs back home. Even when you go to the ER, we don't treat you if you don't have any deposit.

Emma highlighted a historical perspective when she mentioned "…Filipinos they're kind of on the inferiors side." This mindset is derived from the colonial mentality that Filipinos experienced through the colonization of the Philippines by Spain and the United States. This colonization affected how individuals make decisions, where some may be reluctant to challenge status quo. She wanted Filipino American parents to be more assertive to ensure that the child with ASD grows and thrives, and to gain courage to speak their mind if their child is not receiving appropriate care.

Protecting child in social situations. Social situations may be challenging for the child with ASD because the developmental disability affects social skills. Parents have an instinct to protect their child in such situations in which they feel that the child may experience harm from others, such as being teased or bullied. Margaux described her biggest fear about her soon when she drops him off at school:

> Bullying. I'm so scared that way. I'm so scared that he will be bullied in school and he won't know what to do. You know? He wouldn't know how to report. He wouldn't know. I'm so scared with that one and that's so bad. I'm worried about that. And like always tell, I always tell the teachers in IEP, I always tell this parent educator about it, but they always, they always reassure me that Issac actually is strong and he knows how to fight back. Not because he just fights back. No, but he knows how to stand up for himself, is what they're telling me.

Speaking to the IEP teachers is the way that Margaux advocated for her son's safety in school. She was aware about how others may not understand that her son is on the spectrum, and consequently may be teased or harmed for exuding behaviors that may differ from what is socially accepted. Although the IEP teachers reassured Margaux that her son was capable of fending for himself should a bullying situation arise, her natural inclination was to take control of the situation and ensure that potential bullying was on the radar of school personnel.

Specific Aim 3: Explanatory Framework of Filipino American Parental Management of Care for Children and Adults with ASD

The explanatory framework of Filipino American parental management of care for children and adults with ASD involves a complex process integrating four interconnected phases: (1) diagnosis and treatment; (2) daily routines and challenging behaviors; (3) self-reflection and self-awareness; and (4) resilience and strength (see Appendix L). These phases are fluid, as parents describe that over time, there is improvement or regression of social, behavioral, and communication patterns, their management is subsequently affected or changed, and they ultimately reflect upon their management style and parental role.

Diagnosis and Treatment

The diagnosis and treatment phase integrates three forms of parental management: (1) recognizing signs and symptoms of ASD; (2) seeking help; and (3) learning about ASD. This phase encompasses the time prior to the child being diagnosed and extends throughout the child's future growth and development. These three forms of parental management are interlinked, as the recognition of signs and symptoms of ASD leads to seeking help once the parent is ready, and the information provided to the parents at this time increases their understanding and knowledge about the developmental disorder.

Daily Routines and Challenging Behavior

The daily routines and challenging behavior phase involves the following forms of parental management: (1) organizing daily schedules; (2) integrating into social settings; and (3) de-escalating challenging behavior. Parents of children and adults with ASD rely on a routine to provide structure during the day, as the developmental disability manifests having children rely on an established routine. This routine may involve integration into social settings, such as interacting with classmates, peers, and/or family, or outings to various locations, such as stores or theme parks. Challenging behaviors may occur at any time, and may be triggered by certain events, such as deviation from a routine or placement in unfamiliar social settings.

Self-Reflection and Self-Awareness

The self-reflection and self-awareness phase is comprised of three forms of parental management: (1) incorporating self-care; (2) worrying about the future; and (3) navigating cultural awareness. This phase is introspective, where the parents take a reflective stance on their complex role of caring for an individual with ASD. The parents are aware about their interaction with oneself and with others, and how that, in turn, affects the strategies that they use to manage caring for their child with ASD on a daily basis and over time. Many decisions that parents make are based upon how others have treated them, such as health care providers, therapists, and family members, and how cultural beliefs guide decision-making for services and healthcare for their child.

Resilience and Strength

Resilience and strength is the phase that incorporates three forms of management: (1) accepting the diagnosis; (2) defining parenting role; and (3) being an advocate. A diagnosis of an acute, chronic, or terminal illness or a physical or developmental disability brings forth a multitude of emotions due to the impact it places on the affected individual and their caregivers. Emotions, such as anger, grief, or denial, may emerge as the individual (e.g., parent with an infant or a toddler newly diagnosed with ASD) processes the diagnosis. As these emotions are processed, the parent experiences a place of acceptance. This acceptance leads the parents to redefine their parenting role to include unique tasks for the child with special needs, and allows them to come from a place of strength to advocate for their child, who may not have their own voice to advocate for themselves.

Summary

This chapter addressed the specific aims of the research study. Filipino American cultural beliefs and perceptions about ASD were elicited using Kleinman's explanatory model of illness. Causal beliefs of ASD were attributed to various factors—environmental factors, medical conditions, pharmaceutical products, prenatal events, genetic history, and/or superstitious beliefs. Twelve management strategies emerged from the data, rooted in the categories and properties induced from coding processes. These management strategies included the following: (1) recognizing signs and symptoms of ASD; (2) seeking help; (3) learning about ASD; (4) organizing daily schedules; (5) integrating into social settings; (6) de-escalating challenging behavior; (7) incorporating self-care; (8) worrying about the future; (9) navigating cultural awareness; (10) accepting the diagnosis; (11) defining parenting role; and (12) being an advocate. The explanatory framework discussed four different phases involved the Filipino American parental management of care for children and adults with ASD: (1) diagnosis and treatment; (2) daily routines and challenging behavior; (3) self-reflection and self-awareness; and (4) resilience and strength.

Table 1

Filipino American Parent Characteristics

Characteristics		**N = 18**	**%**
Age (years)	31 – 40	5	27.8%
	41 – 50	4	22.2%
	51 – 60	7	38.9%
	61 – 70	2	11.1%
Gender	Female	14	77.8%
	Male	4	22.2%
Marital Status	Single	1	5.6%
	Married	15	83.3%
	Divorced	1	5.6%
	Widowed	1	5.6%
Religion	Agnostic	1	5.6%
	Catholic	15	83.3%
	Protestant	1	5.6%
	Non-denominational	1	5.6%
Education	Associate’s degree	2	11.1%
	Bachelor’s degree	14	77.8%
	Master’s degree	1	5.6%
	Doctorate degree	1	5.6%
Employment	Full-time	11	61.1%
	Part-time	4	22.2%
	Retired	2	11.1%
	Homemaker	1	5.6%
Industry	Education	1	5.6%
	Finance	1	5.6%
	Government/public service	1	5.6%
	Healthcare	9	50%
	Hospitality/tourism	1	5.6%
	Office/administrative	2	11.1%
	Real estate	1	5.6%
	Retail/sales	2	11.1%
Income	$2,000 – $3,999	4	22.2%
	$4,000 – $5,999	1	5.6%
	$6,000 - $7,999	4	22.2%
	$8,000 – $9,999	4	22.2%
	> $10,000	5	27.8%

First Language	English	8	44.4%
	Hiligaynon	1	5.6%
	Tagalog	8	44.4%
	Visaya	1	5.6%
Home Language	English	10	55.6%
	Tagalog	4	22.2%
	English/Tagalog	3	16.7%
	English/Hiligaynon/Tagalog	1	5.6%
Country of Birth	United States	5	27.8%
	Philippines	12	66.7%
	Guam	1	5.6%
Parent Support Group	Yes	10	55.6%
	No	8	44.4%
Health Insurance	Private	15	83.3%
	Public	3	16.7%

Table 2

Filipino American Child or Adult with Autism Spectrum Disorder Characteristics

Characteristics (N = 18)		N	%
Age (Years)	<12	7	38.9%
	12 – 17	2	11.1%
	18 – 21	4	22.2%
	22 – 25	3	16.7%
	26 – 30	1	5.6%
	>30	1	5.6%
Gender	Female	4	22.2%
	Male	14	77.8%
Ethnicity	Filipino/Filipino American	13	72.2%
	Filipino/African American	1	5.6%
	Filipino/Caucasian	1	5.6%
	Filipino/Vietnamese American	3	16.7%
Country of Birth	United States	16	88.9%
	Philippines	2	11.1%
Education (Grade level)	Preschool	2	11.1%
	Kindergarten	1	5.6%
	Elementary school	4	22.2%
	Middle school	1	5.6%
	High school	2	11.1%
	Transition program	3	16.7%
	Trade or vocational school	1	5.6%
	Day program	2	11.1%
	Not enrolled	2	11.1%
Severity of ASD	Mild	7	38.9%
	Moderate	7	38.9%
	Severe	2	11.1%
	Mild to moderate	1	5.6%
	Severe then moderate	1	5.6%
Regional Center	Yes	16	88.9%
	No	2	11.1%
Therapy	Yes	18	100%
	No	0	0%
Types of Therapy	Physical	5	27.8%
	Speech	16	88.9%
	Occupational	10	55.6%
	Behavioral	4	22.2%
Chronic or Mental Health Issues	Yes	10	55.6%
	No	8	44.4%
Medications or Vitamins	Yes	9	50%
	No	9	50%

Ability to Communicate	Yes	17	94.4%
	No	1	5.6%
Language or Mode of Communication	English	15	83.3%
	Tagalog	2	11.1%
	Vietnamese	1	5.6%
	American Sign Language	1	5.6%
	Augmentative and alternative communication	3	16.7%
Additional Help	Yes	17	94.4%
	No	1	5.6%
Types of Additional Help	Babysitter	1	5.6%
	Family	8	44.4%
	Child care	1	5.6%
	Day care	1	5.6%
	Respite care	10	55.6%
Interventions or Treatments	Yes	16	88.9%
	No	2	11.1%
Types of Interventions or Treatments	Applied behavior analysis (ABA)	14	77.8%
	Complementary and alternative medicine	1	5.6%
	Dietary supplements	2	11.1%
	Early Start Denver Model (ESDM)	4	22.2%
	Floortime	3	16.7%
	Relationship development integration (RDI)	2	11.1%
	Sensory integration	2	11.1%
Traditional Filipino Health Healer	Yes	0	0%
	No	18	100%
Health Insurance	Private	2	11.1%
	Public	6	33.3%
	Public and private	10	55.6%
Type of Public Insurance	Medicaid (Medi-Cal)	13	72.2%
	Medicare	3	16.7%

CHAPTER SIX

DISCUSSION

Major Findings

Filipino American Beliefs and Perceptions about ASD

Filipino American parental cultural beliefs and perceptions about ASD were rooted in both modern Western and traditional Filipino belief systems. Through the use of Kleinman's explanatory model of illness, Filipino American parents of children and adults with ASD were able to articulate their perception about ASD within the culture through the context of etiology, symptom onset, severity, illness trajectory, and treatment modalities. These beliefs and perceptions are salient to understanding the processes involved in seeking help and managing care for the child or adult with ASD.

Etiology. The etiology of ASD from the Filipino American parental perspective spanned from biomedical reasons to supernatural causes. The parents reflected upon events preceding the presenting symptoms in which they felt were associated with symptom onset. The causes for ASD noted by the parents in the study—environmental factors, medical conditions, pharmaceutical products, prenatal events, genetic history, and superstitious beliefs—were also noted in prior studies about etiology of ASD (Mercer et al., 2006). Nestor's description of *mangkukulam* (witchcraft) is one that falls under the category of traditional Filipino disease etiology, supernatural causes, which can be healed through non-medical means, such as prayer (McKenzie & Chrisman, 1977; Orque, 1983). Tilahun et al. (2016) also reported that Ethiopian caregivers also believed that possession by spirit was a cause for ASD. Vaccination as a cause for ASD was mentioned by two parents, which have also been noted in prior studies (Mercer et al., 2006). Filipino American parental beliefs about the etiology of ASD varied, but were rooted in their personal experiences during pregnancy or while raising their child.

Symptom onset. Seventeen Filipino American parents reported symptom onset between 8 months and 3 years of age, or 36 months. Although one parent in the study, Orlando, recalled that his son was diagnosed at 18 years of age, the majority of parents observed their child presented with symptoms affecting behavior, communication, social interaction, senses, intellectual levels, motor skills, and overall development at a young age. This finding is most similar to the Taiwanese population, where parents reported symptoms between birth to 36 months of age (Shyu et al., 2016). Parents in Australia noted that symptoms were observed at an earlier age, prior to 30 months (Gray, 1995). The symptoms that affect Filipino American children with ASD varied, as the presentation of ASD in an individual is unique.

Severity. Filipino American parents drew upon their perception of their child's ASD severity through their own observations. The parents in the study were able to identify the symptoms that their child had and compare them to typically developing children without an ASD diagnosis, such as Camille. There was an internal dialogue that the parents verbalized as they determined the level at which their child was affected by ASD using a scale from 0 to 10, where 0 was less severe and 10 and most severe. Parents, such as Efren and Camille, would state the areas in which their child required more assistance and then describe the area in which their child were independent. They also had their own definitions of "0" and "10," such as Camille, where "0" was "normal" and "10" was "nonverbal, nonverbal, incontinent, doesn't socialize at all, barely any interactions." Participants with healthcare backgrounds were also able to use their clinical judgment to discern the severity level of their child as well. Prior studies about ASD in

Australia (Gray, 1995), Ethiopia (Tilahun et al., 2016), India (Sarrett, 2015), and Taiwan (Shyu, et al., 2010) did not address severity in their findings.

Illness trajectory. Filipino American parents believed that their child would have ASD forever because there is no cure. This finding is similar to that of another Western country, Australia, whose parents believed that their children with ASD would not fully recover (Gray, 2010). Similar to Taiwanese families, some of the Filipino American parents described their worries about their child as they integrated into society, especially when transitioning into adulthood (Shyu, et al., 2010). Since there is no cure for ASD, Filipino American parents had to adapt to the situation and seek treatments that they believed were best fit for their child with ASD to help them gain skills in various areas, such as social interactions and communication patterns, as well as devise strategies to address behavioral issues.

Treatment modalities. The majority of treatment modalities for the Filipino American children and adults with ASD were all modern Western-based treatments, including various forms of therapy—speech, occupational, physical, and behavioral, as well as special interventions—ABA, floortime, ESDM, relationship development intervention, and sensory integration. This finding is congruent to treatment modalities found in Taiwanese culture (Shyu, et al., 2010), where the majority of parents utilized therapy to treat their child with ASD, and Indian culture (Sarrett, 2015), where Western-influenced treatments were sought from providers trained in Western medicine. Most of these treatments are those recommended by Western health care practitioners, such as developmental-behavioral pediatricians. In the current study, since half of the participants were in healthcare professions, such as dentistry, mental health, nursing, and respiratory therapy, their training and practice may have influenced the mode of treatment that their child received, as some parents relied on their prior knowledge in educational training, such as nursing school, to help them learn about ASD.

The only form of complementary and alternative medicine treatment utilized by a parent for their child with severe autism was acupuncture and acupressure, which are rooted in traditional Chinese medicine. Filipino Americans have used acupuncture to treat hypertension (dela Cruz & Galang, 2008) and Taiwanese parents have also used acupuncture to treat ASD (Shyu et al., 2010). None of the participants had sought help from a traditional Filipino healer, such as an *albularyo*, *hilot*, or faith healer, although Nestor stated that *albularyos* have been used in the Philippines to treat ASD. This may be due to a small number of Filipinos Americans seeking help from traditional Filipino healers. According to Felicilda-Reynaldo and Choi (2018), utilization of a traditional Filipino healer occurred in 1.3% of Filipino American adults. The use of *hilots* was also used by a small percentage—10.8%—of Filipinos in central Los Angeles (The Historic Filipinotown Health Network, Los Angeles & Semics, LLC, 2007).

Those familiar with such forms of traditional Filipino treatments, such as Catholic prayers or exorcism, were either aware due to stories from previous generations, such as Nida's grandparents, as well as living in the Philippines, such as Nestor, who immigrated to the United States when he was 30 years of age. One parent integrated Western-based dietary modifications, such as one free from dairy, gluten, and preservatives, to ease the symptoms of ASD. Overall, the Western health care system largely influences the treatment modalities that Filipino American parents utilize for their child with ASD.

Filipino American Parental Management of Children and Adults with ASD

Twelve management styles emerged from the study: (1) recognizing signs and symptoms of ASD; (2) seeking help; (3) learning about ASD; (4) organizing daily schedules; (5) integrating into social settings; (6) de-escalating challenging behavior; (7) incorporating self-care; (8) worrying about the future; (9) navigating cultural awareness; (10) accepting the diagnosis; (11) defining parenting role; and (12) being an advocate. These management styles comprised the four phases of an explanatory framework about Filipino American parental management of care for children and adults with ASD: (1) diagnosis and treatment; (2) daily routines and challenging behavior; (3) self-reflection and self-awareness; and (4) resilience and strength.

Diagnosis and treatment. The diagnosis and treatment phase involves the Filipino American parent recognizing signs and symptoms of ASD, seeking help, and learning about ASD. Upon recognizing the signs and symptoms of ASD through their own observations or through the observations of others, the parent sought help for their child. As a collectivist culture, Filipino American families often gather in social events, such as parties, where they interact with other children. At these settings, those attending may share their own opinions about the child with ASD with the parent, such as Ligaya's experience. In Ligaya's case, her sister and sister-in-law urged her to get her son evaluated. As a community, her family was concerned and helped her decide to consult with pediatrician.

The primary Filipino values of *pakikisama* (getting along with others) and *kapwa* (togetherness) were noted in how parents sought help from others. Many parents mentioned that they were able to seek help from other family members to care for their child with ASD. *Pakikisama* was reflected in how these family members assisted the individual with ASD. Through getting along with others, the family members supported and loved the individual with ASD even though the developmental disability may bring forth challenging situations, such as behavioral issues (e.g., tantrums), communication challenges (e.g., unable to verbalize thoughts), or social challenges (e.g., lack of interest playing with others). *Kapwa* was seen through the time spent in social situations, where there was inclusion of the individual with ASD. These cultural values were embedded into the daily care for the individual with ASD.

Learning about ASD was a journey that each parent embarked on upon diagnosis. Each parent had a unique learning curve based on the knowledge that each of them had about ASD from previous personal or professional experience. The parents who had family members with ASD were able to draw upon how their relatives cared for the individual with ASD and were vigilant to notice signs that their own child was developmentally delayed. Likewise, the parents in healthcare professions used their clinical expertise to identify signs and symptoms and subsequently get help. Disclosure of the developmental disability was a sensitive issue for some parents, who only told persons who understood autism. For example, Bernice felt that most people “just don’t understand.” Not understanding may mean a lack of knowledge of ASD in the Filipino American community.

Daily routines and challenging behaviors. The daily routines and challenging behaviors phase includes organizing daily schedules, integrating into social settings, and de-escalating challenging behavior. Filipino American parents develop a daily schedule to maintain a routine for their child with ASD. The parents devise their child’s routine through integrating activities of daily of living, school or programs, therapies or interventions, health care appointments, and social activities. Camille brought up an insightful point about routines, “…it’s pretty much the same thing, just more of it.” Through her lens, raising a child with ASD is similar to raising a typically developing child, but there are added responsibilities. This perception provides a perspective that is inclusive, where she views her son like her other children—ones that still go to school, dentist, and doctor.

Filipino American parents encourage integration of their child with ASD into society through various means. This integration may occur through social events with peers as well as seeing health care professionals to maintain health and wellness. These types of social interaction differ, as playing with peers provide a “personal” environment to interact in, such as a backyard or playground, whereas seeing a dentist provides a “professional” environment to partake in. These different interactions helped build social skills, where the personal environment elicited less formal communication than the professional environment that provided parents a chance to teach their child how to stay calm and act during a health care appointment. Safety was also a skill that parents needed to teach the individual with ASD, as some were not able to discern between safe and unsafe situations.

Challenging behavior was a universal issue that Filipino American parents addressed. Such behavior is present at various degrees, and parents would identify a root cause for the behavior and then strategize a plan to de-escalate the situation. For Filipino Americans, behaviors like outbursts and tantrums may be the cause for stigma, and ultimately *hiya* (shame). There is fear of the individual with ASD if they are not behaving according to social norms. Upon devising a plan to address challenging behavior, Filipino American parents were able to educate others, such as family and friends, about ASD through sharing these strategies.

Self-reflection and self-awareness. The self-reflection and self-awareness phase embodies self-care, worrying about the future, and navigating cultural awareness. Through self-reflection and self-awareness, Filipino American parents are able to be introspective about their child’s diagnosis of ASD. The average PECI score for emotional resources was 2.756, so parents wavered between sometimes and often tapping into emotional resources, such as perception of self-efficacy and competence to help them cope (Bonner et al., 2006). Self-care is a strategy that parents use for themselves as a way to care for their own health as they manage their caregiver role. Finding solace through prayer to God or through a rosary was a management strategy used by many parents of the Catholic faith to cope. This tapped into the trust that these parents had in God, the Filipino secondary traditional value of *bahala na* (placing matters into God's hands). At this point, the parents were able to "let go" and live day-to-day to manage care for their child.

The most significant fear that Filipino American parents expressed was worrying about the future. There was a sense of uncertainty and worry about the future expressed by the parents and also noted by the PECI subscale score of 2.045 for guilt and worry and 2.567 for long-term uncertainty, where a score of 2 would be sometimes having guilt and worry and long-term uncertainty and a score of 3 was often having guilt and worry and long-term uncertainty (Bonner et al., 2006). Two major issues that arose about the future was independence of the individual with ASD and caregiving for the individual with ASD. The goals of many parents were to have their child become as independent as possible. On that note, caregiving would become a future issue. Generational differences emerged when siblings of the individuals with ASD were uninterested or dismissed the possibility of being the primary caregiver in the future. These differences presented a conflict between Philippine collectivism and American individualism amongst the older and younger generations.

Navigating cultural differences was a major issue that manifested in two distinct areas—perceptions about ASD and generational perspectives about ASD amongst the Filipino American community. Perlita's account of recruitment of new members into her Filipino American support group provided insight about *hiya* about the developmental disorder. She faced challenges recruiting due to the *hiya* and stigma that ASD may bring, where some parents did not want to be labeled. As an active member of the support group, which sought to provide Filipino American caregivers with resources and education, she represents a perspective of *kapwa*—establishing a strong bond with other Filipino Americans in the same situation. Members of this group are able to connect with one another on the shared basis of culture and life experience of being a parent of an individual with ASD. An additional cultural sentiment that emerged with support groups included *pakikisama*, where members gather in solidarity and get along with one another, even though each parent may hold their own views or opinions about what is best for their child with ASD. These cultural values shape the foundation of support group for Filipino American parents caring for an individual with ASD.

Generational differences poses challenges to how ASD is perceived in the Filipino American community. Emma's narrative illustrates that a sense of denial about ASD sometimes exists, where the developmental disability is believed not to exist or believed to be a transient phase in which the individual outgrows. This knowledge gap may potentially affect how ASD is diagnosed and treated. Having denial about ASD may prevent the individual from attaining the services or treatments that are necessary to optimize health outcomes.

Resilience and strength. Resilience and strength is the phase that incorporates accepting the diagnosis, defining parenting role, and being an advocate. This phase is an empowering one for the Filipino American parent managing care of a child or an adult with ASD. The point at which the parent accepts the ASD diagnosis is a significant step taken to move forward with attaining care for their child. The mean PECI score for unresolved sorrow and anger was 1.799, so parents wavered between rarely or sometimes experiencing sorrow or anger about the diagnosis (Bonner et al., 2006). Although this phase may initially present with stressful emotions, such as denial, anger and grief, the parent is later able to accept this "new normal" through making lifestyle changes and adjustments, and finding a silver lining. The worldview of the parent is transformed into one in which embraces diversity and inclusion of persons who may be marginalized for various reasons, such as disability or sexuality.

The parenting role was one that is multifaceted, as the responsibilities were beyond simply being a parent. These daily roles, as described by Sofia, included teacher, therapist, caregiver, and nurse. Similarly, Safe et al. (2012) described that mothers experienced "mother as therapist" as a role undertaken to execute the therapies recommended for the child with ASD. Role preparedness, as noted by Tsai et al. (2008), was another experience that parents may face, especially during unexpected life events. In contrast, Elisa encountered a lack of role preparedness due to her husband's death and suddenly had to absorb the role of mother and father in addition to responsibilities she had for her son with ASD. However, there was a sense of pride when parents felt that they were being the most influential figure for their child, as illustrated by Margaux. Over time, Elisa also reached this point, where she stated, "I need to be the voice for my son… I'm not gonna to be afraid of his diagnosis. I'm not gonna be ashamed of his diagnosis." The Spanish-influenced value of *amor propio* (self-esteem) was evident, as both mothers highly regarded their roles as mother.

Last, Filipino American parents embarked as advocates for their child with ASD. There may be barriers to obtaining services and therapies for the individual with ASD. These issues may stem from lack of insurance coverage or denial of services by an organization. Camille exercised her viewpoint in her attempts to attain a 1:1 aide for her son at school. Despite being denied by the school district, she found an advocate to ensure her son attained the services he needed to thrive. Additionally, Filipino American parents took proactive measures to ensure that their child remained safe under the care of others. However, the extent to which a parent may advocate for their child may be hindered by colonial mentality due to Philippine colonization by the United States and Spain. Through managing their challenges and experiencing successes, Filipino American parents as caretakers for a child or an adult with ASD embodied the value of *lakas ng loob* (internal resilience), which provided them with a source of strength during challenging times.

Study Implications

Implications for Research

Findings from this study impact future research efforts for the Filipino American community. As the first study about Filipino American and ASD, the findings provide the groundwork for research in developmental disabilities for this population. Using qualitative methods, findings identified how ASD is perceived in the Filipino American population, and provided Filipino American parents with a voice to share their experiences. Caring for children and adults with ASD in the Filipino American community requires parents to engage in various roles beyond the role of mother and father, such as caregiver, teacher, and advocate. Future research needs to develop and explore interventions specifically targeted to provide Filipino American parents and the community across several generations with knowledge about ASD and strategies to help manage caring for children and adults with ASD. Moreover, the issue of acculturation could further be explored in the context of Filipino American parents' help-seeking behavior for the individual with ASD.

Implications for Practice

Integrating cultural awareness about ASD in the Filipino American community is necessary to provide culturally-sensitive care for patients with ASD and their caregivers. From the time of diagnosis to providing care across the continuum, care plans should integrate strategies to educate others about ASD. Many participants in the research study described the generational gap about ASD, where the “older generation” felt that the developmental disability would be outgrown by the individual over time or through a cure, or expressed denial that ASD was a developmental disability. Culturally-tailored material and programs about ASD in Filipino languages would be fruitful to educate the population about this developmental disability.

Strengths and Limitations

Strengths

Strengths of this research study include the diverse range of research participants. The study enrolled both Filipino American mothers and Filipino American fathers of both children and adults with ASD. Capturing the experiences of both mothers and fathers provided unique perspectives on parental role, as social roles are largely influenced by both culture and mainstream society. Moreover, ASD is a developmental disability that is present across the life span, from infancy to late adulthood. Each life stage is unique, and parental management at each stage changes, such as transitioning from adolescence to young adulthood. Cultural awareness during health care delivery optimizes patient outcomes. Through focusing this study on Filipino American participants instead of the Asian American population at-large, the findings can impact the direction of future care specifically for Filipino Americans diagnosed with ASD.

Limitations

The limitations of this research study involve recruitment methods and generalizability. Autism spectrum disorder, in general, is a developmental disability that is stigmatized, especially in vulnerable populations like the Filipino American community. Recruitment methods could have been strengthened through integrating social media to reach out to potential participants and using technology for data collection. Social media, such as Facebook, Instagram, and Twitter, are modes of communication that many individuals use to connect with others, such as friends, families, businesses, or organizations. Many posts provide others with real-time information that can be easily shared with their social network. This mode of communication could have reached a wider network of potential participants. Additionally, data collection using an encrypted online platform, such as REDcap, for the demographic questionnaire, ASASFA, and PECI, and using encrypted videoconferencing, such as Zoom, may also serve to work with participants' schedules better. Some participants were concerned about childcare or respite services if they were partaking in various tasks, such as running errands, attending events, or going to appointments.

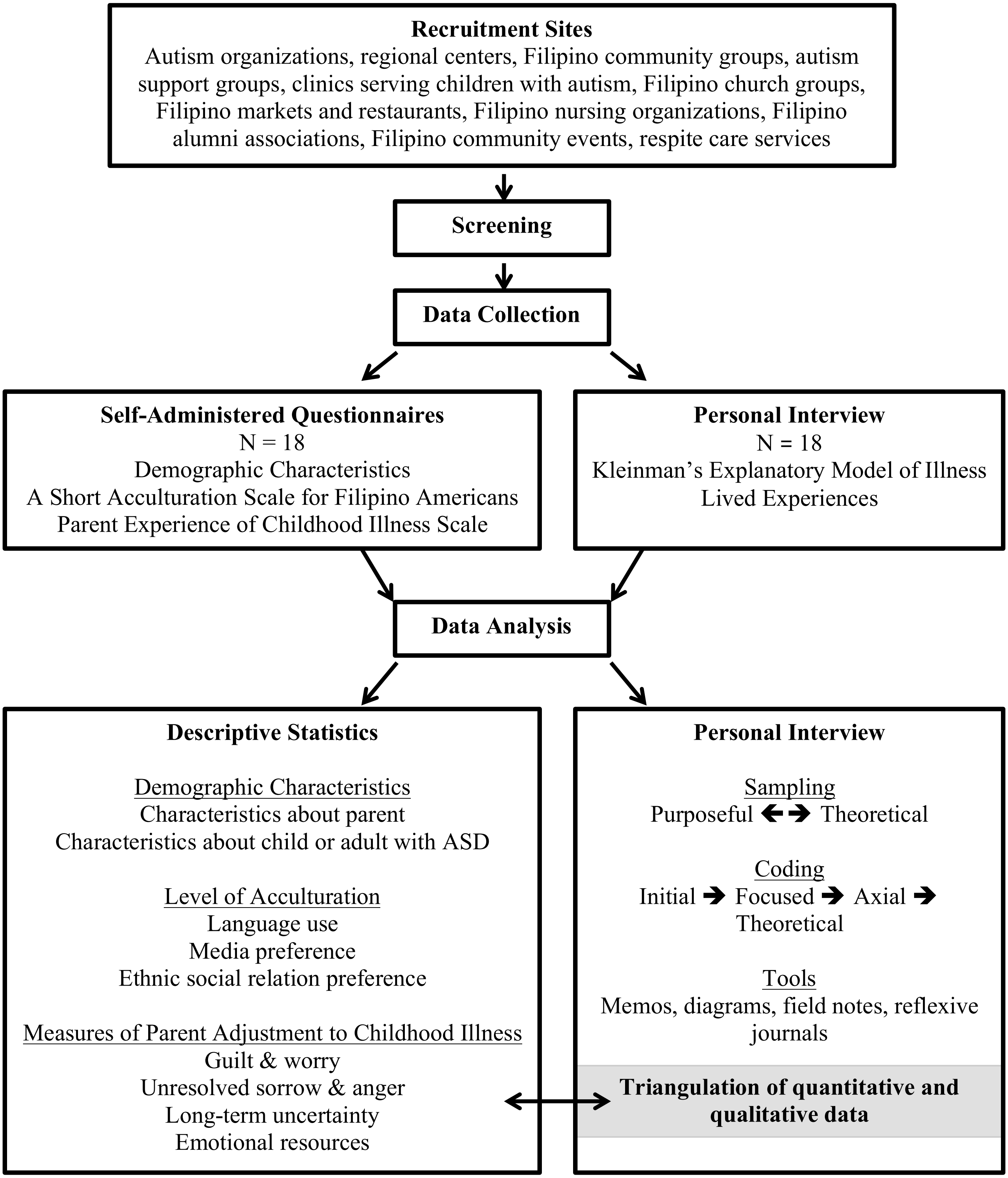
The nature of qualitative research yields in-depth exploration of phenomenon rather than generalization of findings (Corbin & Strauss, 2015). The study sample, however, posed limitations based on sociodemographic characteristics. Most of the participants were female, completed at least a bachelor's degree, earned a median monthly income of $8,000, and worked in healthcare professions. Although efforts were made to recruit within the community, such as Filipino community groups, Filipino church groups, Filipino markets and restaurants, and Filipino community events, many who enrolled were familiar with ASD from their professional experiences, such as healthcare or education. Moreover, the median income of $8,000 was attributed to the participants who worked in healthcare. The combination of clinical knowledge and access to services and resources may differ for an individual working in a different industry and/or earning lower monthly income. Last, some Filipino American fathers who were eligible for the study deferred participation to the mother, whom they felt were more knowledgeable about the daily management of care for the individual with ASD.

Conclusion

Autism spectrum disorder is a developmental disability that uniquely affects each individual. Cultural understanding of ASD is necessary to provide tailored care to the individual to promote development and optimize health outcomes. Within the Filipino American community, ASD is shamed and stigmatized, and negative consequences may result if the individual does not receive appropriate early intervention. Many traditional Filipino cultural beliefs and perceptions, such as *hiya*, *pakikisama*, *kapwa*, *lakas ng loob*, and *bahala na,* a Spanish-influenced value, *amor propio*, and historical influences, such as colonial mentality, affect how ASD is perceived and managed by this community. Findings from this study highlight that increased education about ASD across generations within the Filipino American community and culturally-tailored screening, programs, and interventions are crucial to ensure that each individual with ASD is able to reach their full potential. Raising awareness about ASD in the Filipino American community through education, research, and practice is essential to further understand this developmental disability, which has no cure, throughout the lifespan.

Appendix A

Research Design



Appendix B

Recruitment Letter

UNIVERSITY OF CALIFORNIA, LOS ANGELES
RECRUITMENT LETTER

Filipino American Parental Beliefs and Perceptions about Managing Care for Children or Adults with Autism Spectrum Disorder

Date **[MONTH, DAY, YEAR]**

Dear **[NAME]**,

My name is Sharee Anzaldo, and I am a PhD Candidate at the University of California, Los Angeles (UCLA) School of Nursing. I am inviting you to participate in a research study about how Filipino American parents manage care for a child between 2 and 17 years old or an adult 18 years or older diagnosed with autism spectrum disorder (ASD).

To determine if you will be eligible to participate in this research study, I will ask you questions over the telephone. If you meet the criteria for eligibility, we will schedule a day, time, and place to meet and discuss the research study, answer questions that you may have about the research study, sign the consent form, complete three questionnaires about you and your son or daughter with ASD, and participate in a personal interview that will be audiotaped. Your participation will last approximately 90 minutes to 2 hours, and I may have to follow up with you after the interview if necessary for more information or clarification on any comments made during the personal interview. The information will be used to learn about the cultural beliefs and perceptions that Filipino American parents have about ASD, and to generate knowledge about how this cultural group manages care for a child or an adult with ASD. You will receive a $30 gift card to Target for your time.

Participation in this research study is voluntary, and information garnered from the questionnaires and the interview will remain confidential. If you are interested in participating in this research study, or have any questions, please contact me via phone,   , or via email,   .

Thank you for your time.

Sincerely,

Sharee Anzaldo, MS, RN, PHN, CPN
PhD Candidate
UCLA School of Nursing
Phone:
Email:

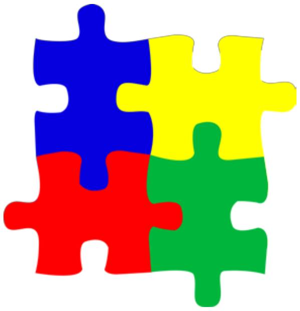
Appendix C

Recruitment Flyer

Research Study

University of California, Los Angeles (UCLA)
School of Nursing

Filipino American Parental Beliefs and Perceptions about Managing Care for Children or Adults with Autism Spectrum Disorder



If you are a Filipino American parent of a child or an adult diagnosed with autism spectrum disorder, you may be eligible to participate!

What is this research study about?

Filipino American cultural beliefs and perceptions about autism spectrum disorder
Filipino American parents managing care for a child or an adult with autism spectrum disorder

Who can participate in this research study?

Self-identified Filipino American parents (mother or father) 21 years or older
Parent of a child between 2 and 17 years old or an adult 18 years or older diagnosed with autism spectrum disorder
Parent must be able to read, write, understand, and speak English
Parent and child or adult must live in Southern California
Child must reside with parent

What will I have to do for this research study?

Complete questionnaires about you and the child or adult with autism spectrum disorder
Participate in an audiotaped interview

What will I receive for participating in this research study?

Eligible participants will receive a $30 Target gift card

Who can I contact for more information about this research study?

Please contact Sharee Anzaldo, MS, RN, PHN, CPN, PhD Candidate
UCLA School of Nursing

Appendix D

Screening Consent Script

UNIVERSITY OF CALIFORNIA, LOS ANGELES
SCREENING CONSENT SCRIPT

Filipino American Parental Beliefs and Perceptions about Managing Care for Children or Adults with Autism Spectrum Disorder

Thank you for calling me regarding the research study about Filipino American parents managing care for a child or an adult with autism spectrum disorder. I would like to ask you several questions to determine your eligibility to participate in the research study. Before I begin the screening process, I would like to tell you a little bit about the research study.

The purpose of the research study is to learn more about how Filipino American parents manage care for a child or an adult with autism spectrum disorder. Very little is known about how autism spectrum disorder affects children or adults and their families in this population. It is important to gain a deeper understanding of this topic to develop culturally-tailored programs for the Filipino American community affected by this developmental disability.

Would you like to continue with the screening process? The screening process will take about 15 to 20 minutes. I will ask you questions about yourself and questions about the child or adult with autism spectrum disorder. You do not have to answer any questions that you do not wish to answer or are uncomfortable answering, and you may stop at any time. Your participation in the screening process is voluntary.

Your answers will be confidential. No one will know your answers except for the research team. If you do not qualify for the research study, your answers will be kept without your name in a locked cabinet at the research office. If you qualify for the research study, decide to participate, and sign the informed consent form, your answers will be kept with the research record in a locked cabinet at the research office.

Would you like to continue with the screening process?

*If **NO,** thank the person and hang up.*

Thank you for your time.

*If **YES,** continue with the screening process.*

I will ask you several questions about yourself and the child or adult with autism spectrum disorder.

1. Do you identify as a Filipino American parent?

   YES: Eligible
   NO: Ineligible

2. Are you 21 years or older?

   YES: Eligible
   NO: Ineligible

3. Are you a parent of a child between 2 and 17 years old or an adult 18 years or older diagnosed with autism spectrum disorder?

   YES: Eligible
   NO: Ineligible

4. Are you able to read in English?

   YES: Eligible
   NO: Ineligible

5. Are you able to write in English?

   YES: Eligible
   NO: Ineligible

6. Are you able to understand English?

   YES: Eligible
   NO: Ineligible

7. Are you able to speak English?

   YES: Eligible
   NO: Ineligible

8. Has a licensed health care provider diagnosed the child or adult with autism spectrum disorder?

   YES: Eligible
   NO: Ineligible

9. If the child is between 2 and 17 years old, do you have custody of the child?

   YES: Eligible
   NO: Ineligible
   NOT APPLICABLE: Eligible [adult is 18 years or older]

10. If the child is between 2 and 17 years old, do you live with the child?

    YES: Eligible
    NO: Ineligible
    NOT APPLICABLE: Eligible [adult is 18 years or older]

11. Have you been diagnosed with a cognitive impairment (e.g., memory loss)?

    YES: Ineligible
    NO: Eligible

12. Do you live in Southern California?

    YES: Eligible
    NO: Ineligible

Thank you for answering the screening questions.

*If **ELIGIBLE,** proceed with the following:*

Would you like to participate in the research study?

> *If **YES,** proceed with the following:*
>
> We will schedule a day, time, and place to meet and discuss the research study, answer questions that you may have about the research study, sign the consent form, complete three questionnaires about you and your son or daughter with autism spectrum disorder, and participate in a personal interview that will be audiotaped. Your participation will last approximately 90 minutes to 2 hours, and I may have to contact you after the interview if necessary for more information or clarification on any comments made during the personal interview in a follow-up session. You will receive a $30 gift card to Target for completing the questionnaires and personal interview. Completing any requested follow-up session is not required to receive the $30 gift card.
>
> *If **NO,** proceed with the following:*
>
> Thank you for completing the screening process. I appreciate your willingness to learn about the research study. Thank you again for your time.

*If **INELIGIBLE,** proceed with the following:*

Thank you for completing the screening process. Based on the following responses, **[IDENTIFY SPECIFIC RESPONSES]**, you are ineligible to participate in the research study. I appreciate your willingness to learn about the research study. Thank you again for your time.

Do you have any questions about the screening process or the research study? I am going to give you a couple of telephone numbers to call if you have any questions later. Do you have a pen? If you have questions about the research study, you may call me, Sharee Anzaldo, MS, RN, PHN, CPN, PhD Candidate, at , or Felicia Hodge, DrPH, Faculty Sponsor, at , and she or myself will answer your questions.

If you have questions about your rights as a research subject or if you wish to voice any problems or concerns you may have about the research study to someone other than the researchers, please call the UCLA Office of the Human Research Protection Program at .

Thank you again for your willingness to answer our questions.

Appendix E

Informed Consent Form

UNIVERSITY OF CALIFORNIA, LOS ANGELES
CONSENT TO PARTICIPATE IN RESEARCH

Filipino American Parental Beliefs and Perceptions about Managing Care for Children or Adults with Autism Spectrum Disorder

Sharee Anzaldo, MS, RN, PHN, CPN, PhD Candidate, and Felicia Hodge, DrPH, Faculty Sponsor, from the School of Nursing at the University of California, Los Angeles (UCLA) are conducting a research study.

You were selected as a possible participant in this research study because you are a Filipino American parent of a child or an adult diagnosed with autism spectrum disorder. Your participation in this research study is voluntary.

Why is this study being done?

This research study aims to describe Filipino American cultural beliefs and perceptions about autism spectrum disorder and explore Filipino American parental experiences in managing care for a child or an adult with autism spectrum disorder.

What will happen if I take part in this research study?

If you volunteer to participate in this study, the researcher will ask you to do the following:

- Complete written questionnaires about you and a child or an adult with autism spectrum disorder and your experiences managing care for a child or an adult with autism spectrum disorder.
- Complete a personal, audiotaped interview about Filipino American cultural beliefs and perceptions about autism spectrum disorder and your experiences as a Filipino American parent managing care for a child or an adult with autism spectrum disorder.

How long will I be in the research study?

Participation will take a total of about 90 minutes to 2 hours. If the principal investigator needs more information or clarification after the interview, a follow-up interview may be requested.

Are there any potential risks or discomforts that I can expect from this study?

There are minimal risks involved with participating in the research study, as increased awareness of feelings and emotions may arise during the interview process.

Are there any potential benefits if I participate?

Although there are no direct benefits to your participation in the research study, the information that you provide is valuable to understanding the personal experiences of Filipino American parents managing care for a child or an adult with autism spectrum disorder.

Will I be paid for participating?

You will receive a $30 gift card to Target in person during the interview.

Will information about me and my participation be kept confidential?

Any information that is obtained in connection with this research study and that can identify you will remain confidential. It will be disclosed only with your permission or as required by law. This information will not be used or distributed for future research studies, even if identifiers are removed. Confidentiality will be maintained by means of using a unique identifying number in lieu of personal identity. Completed questionnaires will be sealed in an envelope for immediate transport to the research office and secured under lock and key. Codes will be used in place of participant names to protect identity for the personal interview. Audio recordings will be labeled by the date and identifying number. You will be able to review and edit the transcripts of the audio recordings, and request that any portions be deleted. Only the principal investigator and her faculty sponsor will have access to the questionnaires and audio recordings.

What are my rights if I take part in this study?

- You can choose whether or not you want to be in this research study, and you may withdraw your consent and discontinue participation at any time.
- If you choose not to participate, there will be no penalty to you, no loss of benefits to which you were otherwise entitled, and no effect on any existing services that the child or adult is receiving for autism spectrum disorder at their current agency or organization.
- You may refuse to answer any questions that you do not want to answer and still remain in the research study.

Who can I contact if I have questions about this study?

- **The research team:**
  If you have any questions, comments, or concerns about the research, you can talk to the one of the researchers. Please contact:

Sharee Anzaldo, MS, RN, PHN, CPN, PhD Candidate, by phone: or by email: .

Felicia Hodge, DrPH, Faculty Sponsor, by phone: or by email: .

- **UCLA Office of the Human Research Protection Program (OHRPP):**
  If you have questions about your rights as a research subject, or you have concerns or suggestions and you want to talk to someone other than the researchers, you may contact the UCLA OHRPP by phone: , by email: , or by mail: .

You will be given a copy of this information to keep for your records.

SIGNATURE OF STUDY PARTICIPANT

Name of Participant

Signature of Participant Date

SIGNATURE OF PERSON OBTAINING CONSENT

Name of Person Obtaining Consent Contact Number

Signature of Person Obtaining Consent Date

Appendix F

Demographic Questionnaire

Please answer the following questions about yourself.

1. What is your date of birth? Month: __________ Day: _____ Year: __________

2. How old are you? _____ years

3. What is your gender? ☐ Male ☐ Female

4. What is the highest level of education you have completed?

☐ Less than high school
☐ High school
☐ Some college or university
☐ Associate’s degree
☐ Bachelor’s degree
☐ Master’s degree
☐ Doctorate degree
☐ Trade or vocational school

5. What is your employment status?

☐ Full-time
☐ Part-time
☐ Per diem
☐ Retired
☐ Student
☐ Unemployed
☐ Homemaker
☐ Other: __________ (specify)

If you ARE UNEMPLOYED OR A HOMEMAKER, please skip Question 6 and continue to Question 7.

6. Which best describes the industry you work in?

☐ Agriculture
☐ Architecture/Design
☐ Arts/Entertainment
☐ Business
☐ Communication/Media
☐ Community Service
☐ Construction
☐ Education
☐ Engineering
☐ Finance
☐ Food Service
☐ Housekeeping
☐ Government/Public Service
☐ Hospitality/Tourism
☐ Healthcare
☐ Law/Public Policy
☐ Manufacturing
☐ Marketing
☐ Military
☐ Nonprofit
☐ Office/Administrative
☐ Public Safety/Security
☐ Science/Technology
☐ Social Services
☐ Retail/Sales
☐ Transportation
☐ Other: ________ (specify)

7. What is your best estimate of your monthly household income?

☐ Under $1,000
☐ $1,000 – $1,999
☐ $2,000 – $2,999
☐ $3,000 – $3,999
☐ $4,000 – $4,999
☐ $5,000 – $5,999
☐ $6,000 – $6,999
☐ $7,000 – $7,999
☐ $8,000 – $8,999
☐ $9,000 – $9,999
☐ Over $10,000

8. What is your first language? ____________________ (specify)

9. What language(s) do you usually speak at home? ____________________ (specify)

10. In what country were you born?

☐ United States ____________________ (specify **STATE**)
☐ Philippines ____________________ (specify **PROVINCE**)
☐ Other ____________________ (specify **COUNTRY**)

If you WERE BORN IN THE UNITED STATES, please skip Question 11 and continue to Question 12.

11. If you were not born in the United States, how old were you when you moved to the United States? _____ years

12. What is your current marital status?

☐ Never married ☐ Living with partner ☐ Married
☐ Separated ☐ Divorced ☐ Widowed

13. What is your religious or spiritual preference?

☐ Agnostic ☐ Atheist ☐ Buddhist
☐ Christian/Aglipay ☐ Christian/Catholic ☐ Christian/Iglesia ni Cristo
☐ Christian/Mormon ☐ Christian/Protestant ☐ Christian/Other
☐ Hindu ☐ Jewish ☐ Muslim
☐ Neither religious nor spiritual ☐ Other: ______________ (specify)

14. Are you covered by health insurance?

☐ Yes/public insurance ☐ Yes/private insurance ☐ Yes/public and private insurance
☐ No ☐ Other: __________ (specify)

15. How many children are in your household? _____ child/children (specify)

16. Aside from yourself, do any other parents of your child with autism spectrum disorder live in the home? ☐ Yes ☐ No

If NO OTHER PARENTS LIVE IN THE HOME, please skip Question 17 and continue to Question 18.

17. Which other parent(s) live with your child with autism spectrum disorder?

☐ Biological mother ☐ Biological father ☐ Stepmother
☐ Stepfather ☐ Adoptive mother ☐ Adoptive father

☐ Other: ____________________ (specify)

18. Are you participating in any parent support groups for autism spectrum disorder?

☐ Yes ☐ No

Please answer the following questions about your child with autism spectrum disorder.

19. What is your child's date of birth? Month: __________ Day: _____ Year: __________

20. How old is your child? _____ years _____ months

21. What is your child's gender? ☐ Male ☐ Female

22. What is your child's ethnicity? ____________________ (specify)

23. In what country was your child born?

☐ United States ____________________ (specify **STATE**)
☐ Philippines ____________________ (specify **PROVINCE**)
☐ Other ____________________ (specify **COUNTRY**)

If your child WAS BORN IN THE UNITED STATES, please skip Question 24 and continue to Question 25.

24. If your child was not born in the United States, how old was he or she when they moved to the United States? _____ years _____ months

25. What type of school and/or program does your child currently attend? (select all that apply)

☐ Public school ☐ Private school ☐ Home school
☐ Charter school ☐ Special education ☐ Day program
☐ Magnet program ☐ Not enrolled in school/program
☐ Other: __________ (specify)

If your child IS NOT CURRENTLY ENROLLED IN SCHOOL AND/OR A PROGRAM, please skip Question 26 and continue to Question 27.

26. What grade level is your child enrolled in?

☐ Daycare ☐ Preschool ☐ Kindergarten
☐ Elementary school ☐ Middle school ☐ Junior high school
☐ High school ☐ Transition program ☐ Some college or university
☐ Undergraduate ☐ Graduate school ☐ Professional school
☐ Trade or vocational school ☐ Other: __________ (specify)

27. Is your child currently employed? ☐ Yes ☐ No

If your child IS NOT CURRENTLY EMPLOYED, please skip Question 28 and continue to Question 29.

28. Please describe your child's occupation: ____________________ (specify)

29. Have you actively participated in your child's Individualized Education Program (IEP)?

☐ Yes ☐ No

30. How old was your child when you suspected that he or she had autism spectrum disorder?

_____ years _____ months

31. How old was your child when he or she was diagnosed with autism spectrum disorder?

_____ years _____ months

32. What symptoms did your child display that led you to think he or she had autism spectrum disorder? (please describe)

____
____
____
____

33. What do you think caused your child to have autism spectrum disorder? (please describe)

____
____
____
____

34. How do you perceive the severity of your child's autism spectrum disorder?

☐ Mild ☐ Moderate ☐ Severe

35. Does your child receive services from a California Department of Developmental Services regional center?

☐ Yes/Eastern Los Angeles
☐ Yes/Kern
☐ Yes/Orange County
☐ Yes/Tri-Counties
☐ No
☐ Yes/Harbor
☐ Yes/Lanterman
☐ Yes/San Diego
☐ Yes/Westside
☐ Other: __________ (specify)
☐ Yes/Inland
☐ Yes/North Los Angeles County
☐ Yes/San Gabriel/Pomona
☐ Yes/South Central Los Angeles

36. Has your child received special therapies and/or interventions? ☐ Yes ☐ No

If your child HAS NOT RECEIVED SPECIAL THERAPIES AND/OR INTERVENTIONS, please skip Question 37 and continue to Question 38.

37. What types of therapies and/or interventions has your child received? (select all that apply)

☐ Physical ☐ Speech ☐ Occupational
☐ Other: __________ (specify)

38. Is your child able to communicate? ☐ Yes ☐ No

If your child IS NOT ABLE TO COMMUNICATE, please skip Question 39 and continue to Question 40.

39. If your child is able to communicate, what language(s) or mode(s) of communication does he or she use? (select all that apply)

☐ English ☐ American Sign Language (ASL) ☐ Filipino: __________ (dialect)
☐ Augmentative and Alternative Communication (AAC)
☐ Other: __________ (specify)

40. Does your child see any specialists aside from their primary care provider? ☐ Yes ☐ No

If your child DOES NOT SEE ANY SPECIALISTS ASIDE FROM THEIR PRIMARY CARE PROVIDER, please skip Question 41 and continue to Question 42.

41. Which specialist(s) does your child see? (select all that apply)

☐ Adolescent Medicine
☐ Allergy
☐ Anesthesiology
☐ Audiology
☐ Cardiothoracic Surgery
☐ Cardiology
☐ Dentistry
☐ Developmental-Behavioral Pediatrics
☐ Dermatology
☐ Endocrinology
☐ Gastroenterology
☐ General Surgery
☐ Genetics
☐ Gynecology
☐ Hematology
☐ Immunology
☐ Infectious Diseases
☐ Nephrology
☐ Neurology
☐ Neurosurgery
☐ Nutrition
☐ Obstetrics
☐ Oncology
☐ Ophthalmology
☐ Orthodontics
☐ Orthopedics
☐ Otolaryngology
☐ Pain Management
☐ Pathology
☐ Physical Medicine
☐ Plastic Surgery
☐ Psychiatry
☐ Pulmonology
☐ Radiology
☐ Rehabilitation
☐ Rheumatology
☐ Sleep Medicine
☐ Sports Medicine
☐ Transplant
☐ Urology
☐ Vascular Anomalies
☐ Other: __ (specify)

42. Is your child covered by health insurance and/or state program(s)? (select all that apply)

☐ Yes/public insurance ☐ Yes/private insurance ☐ Yes/public and private insurance
☐ Yes/state program ☐ No ☐ Other: __________ (specify)

If your child IS NOT COVERED BY HEALTH INSURANCE OR IS COVERED BY PRIVATE INSURANCE ONLY, please skip Question 43 and continue to Question 44.

43. What type(s) of public insurance and/or state program(s) is your child covered by? (select all that apply)

☐ Medicaid (Medi-Cal) ☐ Medicare
☐ Children's Health Insurance Program (CHIP) ☐ California Children's Services (CCS)
☐ Other: ____________________ (specify)

44. Is your child taking any medications and/or vitamins to help control his or her symptoms related to autism spectrum disorder? ☐ Yes ☐ No

If your child DOES NOT TAKE ANY MEDICATIONS AND/OR VITAMINS TO HELP CONTROL HIS OR HER SYMPTOMS RELATED TO AUTISM SPECTRUM DISORDER, please skip Question 45 and continue to Question 46.

45. List all medications and/or vitamins your child is taking for autism spectrum disorder.

_____________________ _____________________
_____________________ _____________________
_____________________ _____________________

46. Does your child have any other chronic and/or mental health conditions aside from autism spectrum disorder? ☐ Yes ☐ No

If your child DOES NOT HAVE ANY OTHER CHRONIC AND/OR MENTAL HEALTH CONDITIONS ASIDE FROM AUTISM SPECTRUM DISORDER, please skip Question 47 and continue to Question 48.

47. List all other chronic and/or mental health conditions your child has been diagnosed with.

_____________________ _____________________
_____________________ _____________________
_____________________ _____________________

48. Have you taken your child to see a traditional Filipino folk healer to treat their autism spectrum disorder? ☐ Yes ☐ No

If you HAVE NOT TAKEN YOUR CHILD TO SEE A TRADITIONAL FILIPINO FOLK HEALER TO TREAT THEIR AUTISM SPECTRUM DISORDER, please skip Question 49 and continue to Question 50.

49. What type of traditional Filipino folk healer(s) has your child seen? (select all that apply)

☐ *Albularyo* ☐ *Hilot* ☐ Faith healer ☐ Other: __________ (specify)

50. Do you receive additional help from other individuals or services, such as family, friends, or respite care, to assist with caring for your child? ☐ Yes ☐ No

If you DO NOT RECEIVE ADDITIONAL HELP TO ASSIST WITH CARING FOR YOUR CHILD, please skip Question 51 and continue to Question 52.

51. List all additional help you are receiving to assist caring for your child.

______________________	_______________________
______________________	_______________________
______________________	_______________________

52. Has your child received any special interventions and/or treatments for autism spectrum disorder, such as applied behavior analysis, early start, sensory integration, relationship development intervention, dietary supplements, complementary and alternative medicine, and/or floortime? ☐ Yes ☐ No

If your child HAS RECEIVED ANY SPECIAL INTERVENTIONS AND/OR TREATMENTS FOR AUTISM SPECTRUM DISORDER, please continue to Question 53.

If your child HAS NOT RECEIVED ANY SPECIAL INTERVENTIONS AND/OR TREATMENTS FOR AUTISM SPECTRUM DISORDER, you have COMPLETED THE QUESTIONNAIRE.

53. What types of special interventions and/or treatments for autism spectrum disorder has your child received? (select all that apply)

☐ Applied Behavior Analysis (ABA)
☐ Sensory integration
☐ Dietary supplements
☐ Floortime
☐ Early Start Denver Model (ESDM)
☐ Relationship Development Intervention (RDI)
☐ Complementary and alternative medicine
☐ Other: __________ (specify)

If your child HAS RECEIVED DIETARY SUPPLEMENTS AND/OR COMPLEMENTARY AND ALTERNATIVE MEDICINE, please continue to Question 54.

If your child HAS NOT RECEIVED DIETARY SUPPLEMENTS AND/OR COMPLEMENTARY AND ALTERNATIVE MEDICINE, you have COMPLETED THE QUESTIONNAIRE.

54. If your child has received dietary supplements and/or complementary and alternative medicine, please describe the specific type of supplement(s) and/or treatment(s) below:

____
____
____
____

Thank you for your responses.

Appendix G

A Short Acculturation Scale for Filipino Americans: English Version

Instructions: Please **circle** the number that corresponds to your best answer to each question.

1. In general, what language(s) do you read and speak?
   Only Philippine language(s)** 1
   More Philippine language(s) than English..2
   Both equally..3
   More English than Philippine language(s)..4
   Only English 5

2. What language(s) did you use as a child?
   Only Philippine language(s) 1
   More Philippine language(s) than English..2
   Both equally..3
   More English than Philippine language(s)..4
   Only English 5

3. What language(s) do you speak at home?
   Only Philippine language(s) 1
   More Philippine language(s) than English..2
   Both equally..3
   More English than Philippine language(s)..4
   Only English 5

4. In which language(s) do you usually think?
   Only Philippine language(s) 1
   More Philippine language(s) than English..2
   Both equally..3
   More English than Philippine language(s)..4
   Only English 5

5. What language(s) do you usually speak with your friends?
   Only Philippine language(s) 1
   More Philippine language(s) than English..2
   Both equally..3
   More English than Philippine language(s)..4
   Only English 5

6. In what language(s) are the TV programs you usually watch?

Only Philippine language(s)	1
More Philippine language(s) than English	2
Both equally	3
More English than Philippine language(s)	4
Only English	5

7. In what language(s) are the radio programs you usually listen to?

Only Philippine language(s)	1
More Philippine language(s) than English	2
Both equally	3
More English than Philippine language(s)	4
Only English	5

8. In general, in what languages(s) are the movies, TV, and radio programs you ***prefer*** to watch and listen to?

Only Philippine language(s)	1
More Philippine language(s) than English	2
Both equally	3
More English than Philippine language(s)	4
Only English	5

9. Your close friends are:

All Filipinos	1
More Filipinos than Americans	2
About half and half	3
More Americans than Filipinos	4
All Americans	5

10. You prefer going to social gatherings/parties at which the people are:

All Filipinos	1
More Filipinos than Americans	2
About half and half	3
More Americans than Filipinos	4
All Americans	5

11. The persons you visit or who visit you are:

All Filipinos	1
More Filipinos than Americans	2
About half and half	3
More Americans than Filipinos	4
All Americans	5

12. If you could choose your children’s friends, you would want them to be:
    All Filipinos 1
    More Filipinos than Americans 2
    About half and half 3
    More Americans than Filipinos 4
    All Americans 5

**Philippine language(s)—refer(s) to Tagalog, Ilocano, Visayan, or other dialects spoken by Filipinos.

Used with permission from Felicitas A. dela Cruz, DNSc, RN, author of A Short Acculturation Tool for Filipino Americans.

Appendix H

Parent Experience of Childhood Illness Scale (PECI) – Short Form©

This questionnaire is concerned with thoughts and feelings related to parenting a child who is living with, or has experienced, a chronic illness. Read each statement and then try to determine how well it describes your thoughts and feelings **over the past month**. Please **circle** the number that corresponds to your best answer to each question.

	NEVER	RARELY	SOMETIMES	OFTEN	ALWAYS
1. It is painful for me to think about what my child might have been like had s/he never gotten sick.	0	1	2	3	4
2. I am at peace with the circumstances of my life.	0	1	2	3	4
3. I feel guilty because my child became ill while I remained healthy.	0	1	2	3	4
4. I worry about my child's future.	0	1	2	3	4
5. I feel ready to face challenges related to my child's well being in the future.	0	1	2	3	4
6. I worry that I may be responsible for my child's illness in some way.	0	1	2	3	4
7. I worry that at any minute, things might take a turn for the worse.	0	1	2	3	4
8. I worry about whether my child will be able to live independently as an adult.	0	1	2	3	4
9. I have regrets about decisions I have made concerning my child's illness.	0	1	2	3	4
10. I think about whether or not my child will die.	0	1	2	3	4
11. I am aware of the specific ways I react to sadness and loss.	0	1	2	3	4
12. I experience angry feelings when I think about my child's illness.	0	1	2	3	4

	NEVER	RARELY	SOMETIMES	OFTEN	ALWAYS
13. I am afraid of this diagnosis occurring in another member of my immediate family.	0	1	2	3	4
14. I trust myself to manage the future, whatever happens.	0	1	2	3	4
15. I find it hard to socialize with people who don't understand what being a parent to my child means.	0	1	2	3	4
16. When my child is playing actively, I find myself worried that s/he will get hurt.	0	1	2	3	4
17. I believe I will never be as completely happy or satisfied with my life as I was before my child became ill.	0	1	2	3	4
18. My hopes and dreams for my child's future are uncertain.	0	1	2	3	4
19. I am jealous of parents who have healthy children.	0	1	2	3	4
20. I worry that my child's illness will worsen / return.	0	1	2	3	4
21. Seeing healthy children doing everyday activities makes me feel sad.	0	1	2	3	4
22. I worry about something bad happening to my child when s/he is out of my care.	0	1	2	3	4
23. I can get help and support when I need it.	0	1	2	3	4
24. I wake up during the night and check on my child.	0	1	2	3	4
25. When I am not with my child, I find myself thinking about whether or not s/he is ok.	0	1	2	3	4

Used with permission from Melanie J. Bonner, PhD, author of the Parent Experience of Childhood Illness Scale (PECI) – Short Form.

Appendix I

Interview Guide

Introduction

I appreciate the time that you have taken out of your busy schedule today to speak with me about your **[SON OR DAUGTHER]**. I am very interested in learning more about Filipino American cultural beliefs and perceptions about autism spectrum disorder and how Filipino American parents manage care for their son or daughter with autism spectrum disorder. I have some questions that I would like to ask you about your experiences with your **[SON OR DAUGHTER]**. If at any time you feel uncomfortable answering any of the questions or need further clarification, please let me know. You do not have to answer any questions that you do not want to answer. We can always move on to the next question. If you feel like ending this session, we could do so now. I will make sure that your information remains confidential. Do you have any questions? If not, we can get started.

Guiding Questions and Probing Questions

Opening	1. Could you tell me about your **[SON OR DAUGHTER]** with autism spectrum disorder?
Beliefs and Perceptions	2. Could you describe autism spectrum disorder in your own words?
Management	3. What do you know about autism spectrum disorder? • How did you learn about autism spectrum disorder? • Where do you get information about autism spectrum disorder? o Other people? o Other organizations? o Other resources?
Management	4. Could you tell me about the moment when your **[SON OR DAUGHTER]** was first diagnosed with autism spectrum disorder? • When did you find out? • How did you find out? • Who told you about the diagnosis? • Who was with you at the time? o Health care providers? o Family? o Friends? • Where were you at when your **[SON OR DAUGHTER]** was diagnosed? • How did you feel about the diagnosis? • How did you react? • Who did you tell? • How did you tell others? o In person?

	- Over telephone? - Over text messages? - Through email? • How did other persons react to the diagnosis?
Beliefs and Perceptions	5. Could you tell me about what you think caused your **[SON OR DAUGHTER]** to have autism spectrum disorder? • What signs and symptoms did you see?
Beliefs and Perceptions	6. Could you tell me about why you think your **[SON'S OR DAUGHTER'S]** autism spectrum disorder started when it did?
Beliefs and Perceptions	7. How does autism spectrum disorder affect your **[SON OR DAUGHTER]**? • Physical health? • Mental health? • Behavior patterns? • Social interactions? • Communication patterns? • Dietary intake?
Beliefs and Perceptions	8. On a scale from 0 to 10, where 0 is less severe and 10 is most severe, how would you rate your **[SON'S OR DAUGHTER'S]** autism spectrum disorder? • Could you tell me about why you rated the severity of your **[SON'S OR DAUGHTER'S]** autism spectrum disorder in this way?
Beliefs and Perceptions	9. How long do you believe your **[SON OR DAUGHTER]** will have autism spectrum disorder for? • Do you think your **[SON OR DAUGHTER]** will outgrow autism spectrum disorder? • Do you think your **[SON OR DAUGHTER]** will have autism spectrum disorder for their entire life?
Beliefs and Perceptions	10. Could you tell me about the types of treatments or interventions you think your **[SON OR DAUGHTER]** should receive?
Beliefs and Perceptions	11. Could you tell me about what you would like to see from your **[SON'S OR DAUGHTER'S]** treatments or interventions? • What would you like to see the most?
Beliefs and Perceptions	12. Like yourself, I am also a member of the Filipino American community. There are health beliefs, attitudes, perceptions, and practices that are unique to our culture. How do you think Filipino Americans view autism spectrum disorder? • Could you tell me about your experiences talking to other Filipino

	Americans about your **[SON'S OR DAUGHTER'S]** diagnosis of autism spectrum disorder? • Could you tell me about Filipino health beliefs, attitudes, perceptions, and practices? • How did your family react? o Your friends? o Your colleagues? • How did these interactions make you feel?
Management	13. Could you tell me about what it is like being a parent of a **[SON OR DAUGHTER]** with autism spectrum disorder? • How do you plan your day? • How do you manage your time? • How does it feel? • What does managing autism spectrum disorder mean to you? • How would you describe your role as a parent of a **[SON OR DAUGHTER]** with autism spectrum disorder?
Management	14. What is a typical day like caring for your **[SON OR DAUGHTER]** with autism spectrum disorder? • Do you have a daily routine? • If so, could you tell me more about your daily routine? • Are there specific items or supplies that you need each day to care for your **[SON OR DAUGHTER]**? • If so, could you tell me more about these items or supplies? • How do you react when unexpected events happen? • How does your **[SON OR DAUGHTER]** react when their daily routine changes?
Management	15. How is it like when you see your **[SON'S OR DAUGHTER'S]** health care provider(s) and/or therapist(s) for appointments or sessions related to autism spectrum disorder? • How do you prepare for the appointments or sessions? • How do you feel during the appointments or sessions? • What is your **[SON OR DAUGHTER]** like during the appointments or sessions? • How do you understand information given to you during the appointments or sessions? • What do you think about immediately after the appointments or sessions? • How do these appointments or sessions for autism spectrum disorder differ from other appointments or sessions that manage other health care conditions that your **[SON OR DAUGHTER]** may have?

Management	16. Could you tell me about any persons who have helped care for your **[SON OR DAUGHTER]** with autism spectrum disorder? • Could you tell me about the help these persons have provided for you? • How did this help make you feel? • Who provides primary care for your **[SON OR DAUGHTER]**?
Management	17. Could you tell me about any persons who have not been helpful in the care for your **[SON OR DAUGHTER]** with autism spectrum disorder? • Could you tell me about why these persons have not been helpful? • Could you tell me about the situation(s) in which you felt like you were not receiving the help you needed? • How did these persons make you feel?
Management	18. Could you tell me about successful moments that you have experienced while caring for your **[SON OR DAUGHTER]** with autism spectrum disorder? • Could you tell me about what made these moments successful? • How would you apply what you learned from these successful moments to manage care for your **[SON OR DAUGHTER]**? • How did these successes influence your perspective on caring for your **[SON OR DAUGHTER]**?
Management	19. Could you tell me about challenging situations that you have faced while caring for your **[SON OR DAUGHTER]** with autism spectrum disorder? • How did you handle these situations? • Did you ask others for help? • If so, who did you ask? • Could you tell me about any strategies that have worked in handling these situations? • Could you tell me about any strategies that have not worked in handling these situations?
Beliefs and Perceptions	20. Could you tell me about any challenges or problems that your **[SON OR DAUGHTER]** has had due to autism spectrum disorder?
Management	21. How do you cope with caring for a **[SON OR DAUGHTER]** with autism spectrum disorder? • Do you draw upon religious or spiritual beliefs to help you cope? • If so, how do these beliefs influence how you care for your **[SON OR DAUGHTER]**? • How do these beliefs help you manage challenging or difficult situations?
Beliefs and Perceptions	22. Could you describe what scares you the most about your **[SON'S OR DAUGHTER'S]** autism spectrum disorder?

Management	23. How has your life changed since your **[SON OR DAUGHTER]** was diagnosed with autism spectrum disorder? • How has your relationship with your family changed? o Your friends? o Your colleagues? • How did the diagnosis affect your worldview? o Your priorities? o Your goals? o Your dreams? o Your health?
Management	24. Could you tell me about how your **[SON'S OR DAUGHTER'S]** autism spectrum disorder affects your future? • How does this affect the future of others also caring for your child? o Immediate family members? o Extended family members? • How do you feel about your future?
Management	25. Could you tell me about how autism spectrum disorder affects the future of your **[SON OR DAUGHTER]**? • What would you like provided for your **[SON OR DAUGHTER]** in the future? • Who will care for your **[SON OR DAUGHTER]** in the future? • What are your experiences managing care of your **[SON OR DAUGHTER]** as they get older? • Have you been involved in planning your **[SON'S OR DAUGHTER'S]** transition from pediatric to adult health care services? • If so, could you tell me more about this process? • How do feel about the future of your **[SON OR DAUGHTER]**?
Closing	26. Is there anything else that you would like to share about your experiences as a Filipino American parent managing care for your **[SON OR DAUGHTER]** with autism spectrum disorder?

Conclusion

Thank you so much for your time and sharing your experiences with me. This information deepens our understanding of autism spectrum disorder in the Filipino American community.

* Questions about beliefs and perceptions about autism spectrum disorder adapted from Kleinman's explanatory model of illness

Appendix J

Coding Process

Raw Data	Initial Coding	Focused Coding
It's fighting for like services, their school district isn't always easy. I really wanted a 1:1 for him at school. They weren't going to give it to me. I wanted like more speech. I wanted speech and I wanted OT and they wouldn't give that to me either. And the…all he qualified was for adapted PE. So I mean I guess they said he was too developmentally delayed to, to get those services. Yeah. So it's… I mean I understand 'cause they don't want to pay for something that he's not really going to benefit from and that's why they don't want to do it. But, uh, I think, I usually think those that, that they're, they're the ones who probably need it the most… But it is a money thing, so. But I, I managed. I got an advocate and I got other people to help me with that and so now I have a 1:1 [laughs]. It was a lot of fighting, but well, I fought it. I got what I wanted. I didn't get everything, but I got, I got what was most important. The 1:1. Yeah. Well, I actually, I got a 1:1 with his ABA company. So his ABA company that he's with, an outside agency, they provide the 1:1 at his school. That's what I was really fighting for was to have them provide it for him at school versus the school district providing him a 1:1.	Fighting for services Stating school district is not always easy Wanting 1:1 for son at school Recognizing school district will not give son 1:1 Wanting speech and occupational therapies Recognizing school district will not give son speech and occupational therapies Stating son only qualified for adapted physical education Giving reason that school district said son was too developmentally delayed for services Understanding school district perspective Disagreeing with school district perspective Getting an advocate and others to help Attaining 1:1 for son Acknowledging lots of fighting Getting what she wanted most Not getting everything Getting most important service Reiterating fighting for services	Admitting challenges with school district Identifying wants for son's services and therapies Understanding school district Disagreeing with school district Getting help from others Recognizing services received and therapies denied Receiving most important service Fighting for services
Axial Coding	Seeking help 1. Relying on others 2. Fighting for necessary services	
Theoretical Coding	Management during diagnosis and treatment phase	

Appendix K

Field Note

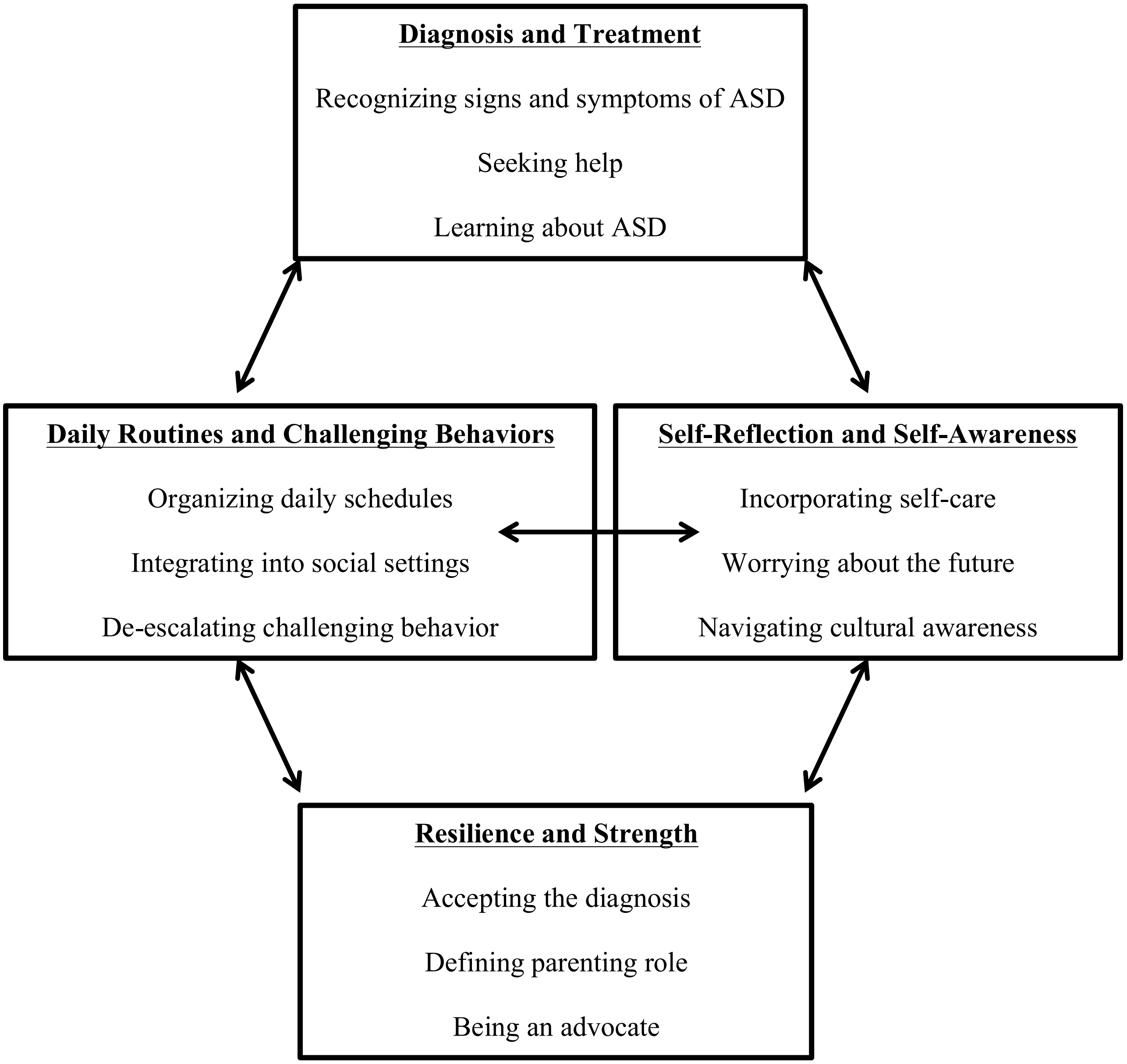
Date	
Time	
Setting	
Participant	

Interview	
Reflection	

Appendix L

Explanatory Framework

Filipino American Parental Beliefs and Perceptions about Managing Care for Children and Adults with Autism Spectrum Disorder



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