

EXPERIENCES OF ACCUMULATED STRESS AMONG
AGING PARENT CAREGIVERS OF ADULTS WITH
AUTISM SPECTRUM DISORDER

by

MONICA A. SCICOLONE

PATRICIA A. PARMELEE, COMMITTEE CHAIR
THEODORE TOMENY, COMMITTEE CO-CHAIR
MEGAN DAVIS
LAURA STOPPELBEIN
DEBRA NELSON-GARDELL
IAN MCDONOUGH

A DISSERTATION

Submitted in partial fulfillment of the requirements
for the degree of Doctor of Philosophy
in the Department of Psychology
in the Graduate School of
The University of Alabama

TUSCALOOSA, ALABAMA

2022

Copyright Monica A. Scicolone 2022
ALL RIGHTS RESERVED

ABSTRACT

With the continuing increased incidence rate of autism spectrum disorder over the decades, there are increasing numbers of adults with autism who require varying levels of lifelong care, typically from parents. It is necessary to understand parents' lived experience of lifelong caregiving, and how their own aging process further impacts life quality. Furthermore, greater understanding of stressors, resources, appraisals, and coping among parent caregivers of children with "high functioning autism" who are transitioning into young adulthood is particularly necessary as services, needs, and experiences for both are nuanced due to functional status, deficits in the service system, and demographic disparities. Given lifespan aspects past research has not addressed, the study focused on development of a measure of parent accumulated stressors, and on interrelations of stressors, perceived social support, future time perspective, burden, satisfaction, and coping on health-related quality of life and meaning in life among 28 parents of young adults with autism. Although proposed quantitative analyses were not completed due to sample size, qualitative analyses on parent experiences and stressors revealed common themes of concern for child's future quality of life, complicated dynamics of providing help to their child overtime, and increased stress related to others' lack of understanding of their child. In total, 10 themes and multiple subthemes were identified in relation to aspects of accumulated stressors. Findings suggest parent stress with this specific population is complex, manifesting in nuanced ways at different life stages. Impacts of the COVID-19 pandemic are also explored, and implications for scientific advancement and clinical services are discussed.

DEDICATION

This dissertation is dedicated to my grandmother, Meeka, who consistently rooted for me and took any moment she could to express her confidence and pride in my passion and work ethic. Although she passed before the completion of my dissertation and graduation, she has remained with me. This is for her.

LIST OF ABBREVIATIONS AND SYMBOLS

α	Cronbach's alpha: a coefficient of internal consistency
M	Mean: sum of a set of measurements divided by number of measurements in the set
N	Total sample size
p	Probability associated with the occurrence under the null hypothesis of a value as extreme as or more extreme than the observed value
SD	Standard deviation: amount of variation or dispersion of a set of data values
r	Pearson product-moment correlation
$<$	Less than
\leq	Less Than or Equal To
$=$	Equal to
CG	Caregiver
ASD	Autism Spectrum Disorder
HFA	"High-Functioning Autism"

ACKNOWLEDGMENTS

Dr. Patricia Parmelee, I cannot thank you enough for your unwavering support, encouragement, wisdom, empathy, and patience with me. You approach mentorship and research with humanity and sticking with me much beyond your retirement shows how much you genuinely care. Thank you for always providing comic relief in my toughest times; there are few things that make me laugh more than Shadow biting your extremities during a Zoom call or reading a new unfiltered email signature that calls out the powers that be. I have no clue where I would be without you, Pat!

Dr. Clayton Shealy, I am so thankful to have you in my life. You have taught me how to be a better clinician and a better person. Thank you for your sincerity in our relationship and for providing me with endless Starbucks gift cards to get me through internship and this dissertation.

Thank you to my supportive and thoughtful co-chair, Dr. Ted Tomeny, and my star committee members who continually enlightened me in their respective areas of expertise. I genuinely learned so much from each and every one of you.

Thank you to the disability community and their families, particularly those with autism and their parents. I am beyond grateful for the parents who took time to participate in this study. During this research process I have found myself overcome with emotions. The personal and deeply emotional accounts of your experiences demonstrate resilience and highlights the reality behind the data points. Thank you for being wonderful parents!

Lastly, thank you to *my* wonderful parent—my mother, my biggest cheerleader. I couldn't have done this without you.

CONTENTS

ABSTRACT.....	ii
DEDICATION.....	iii
LIST OF ABBREVIATIONS AND SYMBOLS.....	iv
ACKNOWLEDGMENTS.....	v
LIST OF TABLES.....	viii
LIST OF FIGURES.....	ix
INTRODUCTION.....	1
Variations in Family Caregivers.....	2
Outcomes for Parent Caregivers of Children with Autism Spectrum Disorders.....	3
Outcomes and Interventions for Adults with Autism Spectrum Disorders.....	4
High-Functioning Adults with Autism.....	6
Parent Caregiver Accumulated Concerns and Stressors.....	8
Satisfaction and Rewards for Parents of Adults with ASD.....	15
Interaction of the Parent’s Aging Process Within Caregiver Processes.....	18
Conceptual Framework.....	22
Purpose of the Study.....	23
METHOD.....	27
Participants and Procedure.....	27
Measures.....	34
Statistical Analyses.....	43

RESULTS.....	47
Phase 1.....	47
Phase 2.....	50
Qualitative Findings: Stressors.....	51
Qualitative Findings: COVID-19.....	59
DISCUSSION.....	63
Phase 1: Cognitive Interviews.....	63
Phase 2: Survey Responses Focused on Accumulated Stressors and Bivariate Correlations...65	
Implications and Future Directions.....	68
Limitations.....	71
REFERENCES.....	75
APPENDIX A ACCUMULATED STRESSORS SCALE (PHASE 1)	89
APPENDIX B COGNITIVE INTERVIEW.....	91
APPENDIX C ASD COLLEGE TRANSITION/SUPPORT PROGRAMS CONTACTED.....	97
APPENDIX D ACCUMULATED STRESSORS SCALE (PHASE 2).....	102
APPENDIX E IRB APPROVAL LETTERS.....	111

LIST OF TABLES

Table 1. Demographics for Phase 1 Interviews (N = 6).....	29
Table 2. Demographics for Phase 2 Participants (N = 28).....	32
Table 3. Frequencies for Accumulated Experiences vs. Appraised Stressors.....	40
Table 4. Descriptives of Proposed Primary Study Variables (N = 28).....	46
Table 5. Common Theme in Cognitive Interview Responses to Specific Probe: Timeframe.....	48
Table 6. Common Theme in Cognitive Interview Responses to General Probe: Stressor Vs. Experience.....	48
Table 7. Cognitive Interview Responses to General Probe: Specific Items to Add.....	49
Table 8. Correlations of the Assessed Variables.....	51
Table 9. Themes and Subthemes: Parent Stressors Missing from Accumulated Stressors Scale.....	52
Table 10. Themes and Subthemes: Difference in Parent Stress in Adulthood vs. Childhood.....	55
Table 11. Themes and Subthemes: Effect of COVID-19 on Parents.....	59
Table 12. Themes and Subthemes: Effect of COVID-19 on Adults with Autism.....	61

LIST OF FIGURES

Figure 1. Applied Double ABCX Model for Aging Parents of Adults with ASD.....26

INTRODUCTION

The first study and description of Autism Spectrum Disorder (ASD) originated almost eight decades ago as the syndrome of infantile autism (Kanner, 1943). Since then, knowledge of ASD has vastly developed, especially over the past thirty years (Volkmar et al., 2013). We now understand ASD as a lifelong neurodevelopmental disorder that significantly impairs communication, socialization, cognition, and adaptive skills. It is an early-emerging disorder, with a definite biological basis (Rutter et al., 2006). Individuals with ASD experience persistent deficits in social communication and interaction across contexts through deficiencies in emotional reciprocity, nonverbal communication, and development and maintenance of relationships. Additionally, distinct behavioral patterns are present, such as repetitive movements or speech, inflexibility of routines, highly restricted fixated interests, and hyperreactivity or hyporeactivity to sensory input (American Psychiatric Association, 2013).

Although there is noteworthy progress in the field of autism, the majority of work focuses on infants and young children (Volkmar et al., 2014). Increased understanding of ASD within early development has no doubt enhanced the lives of those with ASD and their family members in many ways, including earlier diagnoses, improved prognoses with evidence-based interventions, and historically, debunking the negative perception and blame typically inflicted on the parents for their child's behavior (Volkmar et al., 2014; Schopler, 1971). Nevertheless, rigorous focus on the young ASD population has contributed to the dearth of research on ASD in adolescence and adulthood, when development continues. This is particularly problematic because incidence rates have continually increased over the decades, with most recent estimates

at 1 in 54 children with ASD (Centers for Disease Control and Prevention, 2020). In turn, there are increasing numbers of adults with ASD. Given the significant functional impairments associated with ASD, most typically, the family is responsible for lifelong care (Volkmar et al., 2014). Thus, it is essential to identify correlates of caregiving experiences including stressors, resources, satisfaction, burden, and coping among parents of adults with ASD.

Variations in Family Caregivers

The 2015 National Alliance for Caregiving (NAC) and AARP report indicates that the “typical caregiver” is a 49-year-old female caring for an older adult relative with a long-term physical condition. There are also unique caregivers that do not fit the typical profile, such as sandwich generation caregivers, who are “sandwiched” between caring for children as well as an aging family member (Miller, 1981). An even further nuanced sandwich caregiving role exists: a parent caring for an adult child with a developmental disability. Caregiving responsibilities persist through older adulthood, and parents are typically simultaneously “pressed” between caring for themselves as they age and their adult child. As such, Abramson (2015) coined the term “Panini sandwich generation” to describe the distinct and often overlooked caregivers that are outside the bounds of the “typical” or even the “sandwich” caregiver.

The trajectory of hands-on care and independence differs quite a bit from parents of children who do not have developmental disabilities. When the child has reached adulthood, most parents are no longer providing primary care or have substantial involvement in daily life (Abramson, 2015). In contrast, for parents of children with developmental disabilities, the caregiving is usually life-long. Often the adult child continues to live with and/or necessitate substantial care and involvement from the parents (Van Bourgondien et al., 2014). It is estimated that about 75% of adults with developmental disabilities live with family caregivers at home, and

25% of caregivers are over the age of 60 (Fujiura & Park, 2003). Parent caregivers for an adult child with a developmental disability face stressors and experiences that are not shared by their parent counterparts of children without disabilities. Such a distinct and increasingly prevalent type of caregiving role necessitates greater research to develop a better understanding of the parents' lived experience, particularly as they age into late adulthood.

Outcomes for Parent Caregivers of Children with Autism Spectrum Disorders

Parenting for an individual with ASD is associated with higher stress levels and poorer mental health than parenting for those of “typical” development (Montes & Halterman, 2007). Compared to normative cortisol patterns in mothers of children without disabilities, mothers of adolescents and adults with ASD have cortisol profiles characteristic of groups who experience chronic stress (Seltzer et al., 2010). These parents also demonstrate significantly more daily fatigue, stressful events, negative affect, physical health symptoms, and lower positive affect than a nationally representative sample of mothers of children without disabilities (Smith et al., 2010; Smith, Seltzer, et al., 2012).

Further, among parents of children with developmental disabilities, research indicates disparities of stress, mental health, and well-being as a function of the nature of the child's disability. Regarding psychological stress, parents of individuals with ASD report greater depressive symptoms and pessimism (Abbeduto et al., 2004; Seltzer et al., 2000), lower maternal well-being (Blacher & McIntyre, 2006), and higher levels of stress than parents of those with Down syndrome, developmental delays, and cerebral palsy (Dabrowska & Pisula, 2010; Eisenhower et al., 2005; Estes et al., 2009; Pisula 2007). Bouma and Schweitzer (1990) also found higher stress in parents of children with ASD compared to parents of children with a chronic physical condition (cystic fibrosis). Overall, meta-analyses (Hayes & Watson, 2013)

substantiate this; parenting a child with ASD is associated with greater parenting stress as compared with parenting children with typical development or another disability. Of note, parent stress and well-being has consistently been associated with behavior problems and ASD symptom severity across many ages (Abbeduto et al., 2004; Blacher & McIntyre, 2006; Bromley et al., 2004; Lounds et al., 2007; Hayes & Watson, 2013). There is evidence of a tendency for decreases in maladaptive behaviors and symptoms with age (Esbensen et al., 2009); however, these characteristics continue to influence the functioning of individuals with ASD as well as parent caregiver well-being (Blacher & McIntyre, 2006; Lounds et al., 2007). Nonetheless, parent adaptation and well-being are multi-layered and many other aspects, such as psychological factors, appraisals, and coping, play an important role for parent outcomes (Bristol, 1987; McStay et al., 2014; Pakenham et al., 2005). Thus, the current study examines these components associated with health-related quality of life and meaning in life for Panini sandwich caregivers of adults with ASD. This is particularly important given the “autism tsunami” of children with ASD who will be transitioning to adulthood (Maynard, 2015).

Outcomes and Interventions for Adults with Autism Spectrum Disorders

Although the adult ASD literature is small relative to the childhood literature, there are a considerable number of outcome studies (see Howlin, 2013), most of which do not surpass young adulthood. A 10-year prospective study of youth receiving special education services (National Longitudinal Transition Study-2; NLTS2) provides insight on outcomes for individuals with disabilities. In particular, young adults with ASD have lower rates of postsecondary education compared to those with learning disabilities (LD) and speech/language impairments, as well as lower employment rates than young adults with intellectual disability (ID), LD, and speech/language impairments (Shattuck et al., 2012). Across these disability groups, those with

ASD have the greatest risk of disengagement from postsecondary education or employment (Shattuck et al., 2012). This longitudinal study data also suggests that individuals with ASD have low rates of independent living and fewer lifelong friendships (Newman et al., 2009).

Indeed, these are better outcomes compared to the expectation decades ago that full time residential care would be necessary for individuals with ASD. Advances in research and care for children have likely increased the growing proportion of adults with ASD with relatively greater levels of self-sufficiency and independence. For example, in up to 50% of individuals with an IQ greater than 55, there are overall improvements in communication, adaptive skills, and reduced symptom severity; only a minority seem to lose skills (Howlin, 2013). Nevertheless, individuals with greater cognitive ability face struggles surrounding adaptive skills (Volkmar et al., 2014), and even those who make noteworthy functional progress continue to experience difficulties with social interaction and isolation, increasing risk for depression and anxiety (Howlin, 2013). Despite the paucity of research, we know that relationships exist between functional independence, comorbid psychiatric disorders, and social functioning for adults with ASD (Esbensen et al., 2010).

Unfortunately, the focus on intervention and services for infants and young children has detracted from adult intervention studies. In a review of literature published from 2000 to 2010, Shattuck and colleagues (2012) found only 23 papers (of an estimated 11,000) focused on interventions and services to aid adults with ASD aged 18 and older with independent functioning, education, employment, and social participation. Another review found that only 1.7% of 146 assessed intervention studies included participants age 20 or older, with the majority of participants between two to eight years old (Edwards et al., 2012). It is problematic that

intervention and support services for adults have not proportionally increased with the growing prevalence of adults with ASD.

High-Functioning Adults with Autism

This is a problem that extends to adults with Asperger syndrome and “high-functioning autism” (HFA). Before discussing outcomes in these groups, it is important to briefly address historical perspectives of these terms. Asperger syndrome was previously in the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV; American Psychiatric Association, 1994) categorized within Pervasive Developmental Disorders (PDD). Diagnostic criteria consisted of at least two symptoms of social impairment, one symptom of behavioral and interest restriction, and a level of normal cognitive functioning without significant general delay in language. HFA, on the other hand, is not a diagnosable psychological disorder in the DSM, but is sometimes used to describe presentations of ASD (or PDD-NOS) with average or above average IQ (70 or higher) (Giambattista et al., 2019). Although the DSM-5 (American Psychiatric Association, 2013) added ASD, which now encompasses Asperger syndrome and PDD to provide a single continuum with specifiers of impairments and severity levels, confusion and controversy remain regarding the overlap and lack of reliably distinct differentiations between the terms Asperger syndrome and HFA (Giambattista et al., 2019).

Few studies have examined differences in groups of individuals diagnosed at a young age with Asperger syndrome and HFA beyond adolescence. Howlin (2003) examined adults 18 years and older with a nonverbal IQ of 70 or greater who, based on the Autism Diagnostic Interview-Revised (ADI-R; Rutter et al., 2003), met criteria for age of onset, impairments in communication and social interactions, and stereotyped behaviors, some of whom had shown early delays in language (deemed HFA in the study), and some of whom were reported to not

have those delays in childhood (deemed Asperger syndrome in the study). The absence of substantial difference between the two diagnostic groups in adulthood in this sample suggests that HFA and Asperger syndrome may not be distinct conditions, or at least that differentiations made in early childhood become less prominent with age (Howlin, 2003). Beyond this, Howlin (2003) emphasizes the unfavorable prognosis across both groups, including high dependence on families for support, lack of close friends, and low levels of employment.

It is important to note the nuanced outcomes for those with HFA. Individuals with ASD and comorbid ID demonstrate lower levels of social functioning compared to those with ASD and higher IQ scores (Eaves & Ho, 2008; Howlin, 2004). However, even for these individuals with high IQ, studies show that 50–60% live with family members and about 30–35% live in residential placements throughout adulthood (Eaves & Ho, 2008; Levy & Perry, 2011), another notable reason why the notion of “HFA” may come under scrutiny by some. In a sample of young adults with ASD transitioning to adulthood, Taylor and Seltzer (2011) found that 47% of young adults without ID were enrolled in a post-secondary education program and 12% were competitively employed, compared to 2% and 4% of young adults with ID, respectively. On the other hand, while only 6% of those without ID received adult day services, 74% of adults with comorbid ASD and ID received adult day services. Finally, young adults with ASD without ID were three times more likely (24%) than those with comorbid ASD and ID (8%) to have no regular formal daytime activities that are typical for developmental disabilities (e.g., supported employment, sheltered workshop, day habilitation program, individualized programs with support). Those with no day activities showed greater functional independence and less severe ASD symptoms and maladaptive behaviors than those obtaining adult day services, but had less functional independence and more severe ASD symptoms and maladaptive behaviors than those

in post-secondary programs or competitive employment. During a 12-year longitudinal study by Taylor et al. (2015), two-thirds of adults with ASD and average-range IQ held competitive employment or postsecondary education, but less than a quarter maintained these activities over this timeframe. Behavioral characteristics (independence in activities of daily living, maladaptive behaviors, autism symptoms) were detected between adults who have never had competitive employment/postsecondary education and adults who sometimes participated in these activities, but were indistinguishable between adults who sometimes participated from those who were consistent in their maintenance of employment or postsecondary education.

Thus, it is important to keep in mind how those with HFA (or even “mid-level” functioning) may differ in presentation, obtainment of services, and parent caregiver processes/outcomes. Given the heterogeneity of the disorder, disparities in diagnoses and services by race and SES (Mandell et al., 2009; Williams et al., 2019), and ever-evolving research regarding adaptations of historical perspectives, there is understandable variability in outcome studies. Nonetheless, it is evident that young adults with ASD, as well as their aging parents, have unique concerns and challenges that research has not addressed. The purpose of the current study is to investigate interrelations of enduring caregiver-related demands and components of the aging process on health-related outcomes for Panini sandwich caregivers of adults with ASD.

Parent Caregiver Accumulated Concerns and Stressors

Transition Into Young Adulthood

Parents of young adults with ASD (ages 18 to 26) worry significantly more about myriad aspects regarding transition to living and working environments post high school than parents of young adults with Down syndrome, cerebral palsy, and learning disabilities (Blacher et al.,

2010). Access to and quality of crucial services for both the individual with ASD and the family substantially vary across the lifespan and across the country (Volkmar et al., 2014). Through age 21, the entitlement system surrounding the Individuals with Disabilities Education Act (IDEA) ensures special education services through the public schools. At age 22, services move from an entitlement to an eligibility system. This shift is a multilayered stressor for parents. Distinct state bureaucracies (Medicaid and vocational rehabilitation) now provide services, unlike IDEA services delivered by an entity parents have been familiar with for most of their child's life (Bagenstos, 2015). Further, services aren't delivered directly from state government systems, but are instead contracted with outside providers (e.g., units of local government, nonprofit organizations, for-profit corporations; Bagenstos, 2015). Although parents of children with ASD are accustomed to serving as their child's advocate, navigating new bureaucratic systems can be overwhelming and often evoke feeling back to "square one" (Van Bourgondien et al., 2014). Moreover, with transition to an eligibility system, many with ASD lose entitlements and services they had been receiving since initial diagnosis, particularly if they have higher cognitive ability (Volkmar et al., 2014). These systemic changes add to the stress on aging parents to learn and coordinate other services and supports for their adult child.

More individuals with ASD, particularly those with HFA, are enrolling in college and postsecondary programs (VanBergeijk et al., 2008). This setting and life transition provide opportunities for greater autonomy, but are added, somewhat contradictory, stressors for parents. Parents are no longer able to serve as hands-on advocates, including active involvement in their child's Individualized Education Plan (IEP), advocating for services, and meeting with teachers. Instead, greater responsibility is on the adult with ASD to coordinate accommodations and advocate for oneself, which requires preparation both from the young adult and the parents

(Palmer, 2006). Nevertheless, parents maintain an important level of involvement, more so with nonacademic aspects, such as self-care, organizational skills, and social skills (Palmer, 2006). Overall, it is a challenge for parents to balance autonomy of their adult child, while remaining involved where needed to optimize their well-being and development. Morrell and Palmer (2006) note the “letting go” process as particularly difficult for parents of an adult with ASD because they are accustomed to assisting and protecting their child due to essentially lifelong vulnerabilities.

An additional complex concern is identifying the appropriate living context for the adult child (e.g., co-residing in the parents’ home, living independently, semi-independently, or in a residential program or group home). This aspect of the young adulthood transition seems to be multi-faceted, particularly for mothers. In co-residing contexts, mothers have peace of mind regarding the safety and well-being of their child, yet experience strain related to caregiving activities. When the adult child does not live at home, mothers feel a sense of freedom yet affectively miss their child (Krauss et al., 2005). Most young adults do continue to live with parents/family (Volkmar et al., 2014). For those who do not, much parent-child contact is maintained (Krauss et al., 2005). Overall, irrespective of living situation, individuals with ASD remain highly dependent on parent support (Howlin, 2004), and parent concern for their care persist (Van Bourgondien et al., 2014).

Concerns About the Future and Future Planning

Parents of children with ASD experience anxiety and worry associated with long-term outcomes/functioning, and particularly concerns about their child’s future when they are no longer able to serve as a caregiver (Bayat, 2007; Dudley et al., 2019; Heller et al., 2007).

Parent’s paramount concerns surround where their child will reside, work, and who will provide

care for them when they are no longer able or when they have passed (Van Bourgondien et al., 2014). Although their concern surrounding the future is substantial, many parents have yet to make solid future plans (Pryce et al., 2017; Van Bourgondien et al., 2014), and long-term care planning for their child is an additional stressor faced by Panini sandwich caregivers (Abramson, 2015). Particularly for older caregivers, the need to plan for the future care of a family member with a developmental disability contributes to their experienced stress and sense of “unfinished business” (Smith & Tobin, 1990; Smith et al., 1995). Key topics such as financial and estate planning, future living arrangements, residential placement, guardianship, vocational and recreational planning, and general lifestyle choices necessitate deliberate decision-making (Heller & Caldwell, 2006). The complex and therefore daunting nature of specific aspects of future planning, such as legal and financial information, can impede parents’ actions to make future plans (Heller & Caldwell, 2006). Overall, planning for the future is a complicated, arduous, and emotional process, and information on future planning is among the highest unmet needs reported by older caregivers. Thus, Heller and Caldwell (2006) implemented a future planning peer support intervention for aging caregivers and adults with developmental disabilities. The intervention significantly contributed to completion of specific future planning outcomes and reduced feelings of caregiver burden compared to the control group. Further, daily choice making increased for the care recipients. Burke and Heller (2016) found that future planning is related to increased caregiver satisfaction in parents of adults with ASD, and also greater caregiving satisfaction and self-efficacy when the adult with ASD has less choice making ability. Noted recurring barriers to future planning include ability to trust professionals, emotional struggles with the service system, and reflecting on one’s own mortality (Heller & Caldwell, 2006).

Parents of adults with ASD who are high functioning may be in a particularly stressful position given the distinct and personalized characteristics of their adult child's level of cognitive functioning, independence, and persisting impairments in certain areas. The decisions, like the disorder itself, lie on a spectrum. For example, parents need to make decisions about guardianship once their child turns 18 years of age. For those with severe impairment or ID comorbid with ASD, parent decisions may be more straightforward, involving petitions for full guardianship. But parents of a high functioning child face a worrisome predicament. They may feel caught between withdrawing their child's decision-making abilities and rights in order to protect them, or respecting their desire for independence despite deficits in judgment and functioning (Van Bourgondien et al., 2014). Partial guardianship is an option, however, even decisions of partial guardianship may be ambiguous for individuals with HFA. Although higher functioning individuals may seem to require less support, comparable long-term planning is usually required (Van Bourgondien et al., 2014).

Services and Unmet Needs

Given the heterogeneity of the disorder and the quality of services delivered, needs of this parent population are diverse and variable (Eaves & Ho, 2008; Hare et al., 2004; Shattuck et al., 2012). However, required assistance for parents and families is mostly comparable with that needed during childhood (Bromley et al., 2004). Unfortunately, parents' abilities to keep up with identifying and acquiring services can deteriorate with age (Van Bourgondien et al., 2014). Additionally, many parents are unaware of intervention options for their adult child with ASD, a stark difference from parents of young children with ASD who tend to ask for a specific intervention by name (Hare et al., 2004; Van Bourgondien et al., 2014). Researchers have noted inadequacies in service training, staff retention, knowledge, and intervention techniques for

adults with ASD, leaving many without appropriate services (Gerhardt & Lanier, 2011). In a recent study examining unmet needs and service usage for adults with ASD (Dudley et al., 2019), over half of the middle age to older adult parents reported need for more services. Particularly, for those who live in the family home, caregivers were more likely to need more services and report lack of knowledge or awareness of where/how to obtain services compared to caregivers of adults who reside in supported living facilities. In this study, other than living situation, age was the only other predictor of need for more services: caregivers of older adults with ASD reported greater unmet needs. Overall, the most frequent needs reported were employment services and daytime support/day programs, followed by services for social interactions for the adult care recipient with ASD (Dudley et al., 2019).

Further, the developmental disability service system remains inadequate in its service and accommodations for idiosyncratic needs of adults with ASD who are deemed high functioning. Adults may fall through the cracks of the system if they are considered not “severe enough,” yet have enough impairments that they are unable to function or live to their maximum potential independently (Taylor & Seltzer, 2011). To significantly improve long-term outcomes for both individuals with ASD and their parents, there is substantial need for improved ASD-focused adult services generally, and particularly for HFA. These deficits in the service system contribute to stress and burden for parents of adults with HFA in transition to young adulthood and beyond. Parents have also addressed unmet needs related to desired social outlets for adult offspring (social programs, friends, individuals to spend time with outside of the house; Eaves & Ho, 2008). Without these outlets, parents and other family members spend increased time with their child and decreased time in their own activities or self-care. For aging parents, these competing demands for their adult child and their own aging process may generate increased stress.

Self-Care and Social Support

An array of factors determine the amount and type of involvement needed from parents, but studies suggest that parents continue to serve as the adult's primary caregiver and/or primary source of support (Howlin, 2004). Compared to mothers of children of typical development, mothers of adolescents and adults with ASD spend increased time caretaking, doing household chores, and less time partaking in leisure activities (Smith et al., 2010). Qualitative studies (Marsack & Perry, 2018) have examined how the persisting ASD caregiver role can contribute to social exclusion, including stigma and misunderstanding of ASD, intricacies of the caregiving role, and impacts on daily routines. Parents have difficulties obtaining relief from caregiving (Krauss et al., 2005). Thus, many endorse unfavorable social deficits, including less involvement in activities/events, decreased time available to spend with family/friends, and feeling their lives are restricted due to caregiving demands (Altiere & von Kluge, 2009; Hare et al., 2004). This is problematic since social support bolsters physical and psychological well-being in general (Sorkin et al., 2002), and particularly for individuals under chronic stress, such as caregivers (Cohen, 2004). In fact, parents aged 50 or older of an adult child with ASD typically experienced less caregiver burden if they had informal social support from friends/family to assist with care. Formal social support did not mediate the relationship between caregiver burden and quality of life (Marsack & Samuel, 2017).

Smith, Greenberg, et al. (2012) examined associations of psychological well-being with both quantity and valence of emotional support (positive and negative) in mothers of adolescents and adults with ASD. Results showed a larger social network related to lessened maternal depressive symptoms and greater positive affect over 18 months, even after controlling for child behavior problems. Negative support (conceptualized here as criticism, blame, excessive

demands, feelings of discomfort) was the most substantial predictor of well-being, predicting increased depressive symptoms, negative affect, and decreased positive affect. Interestingly, positive support did not predict changes in well-being. This may be the case because negative support can have a particularly harmful impact for those with heightened life stress (Ingersoll-Dayton et al., 1997).

Of note, with the current COVID-19 pandemic, there are stresses, uncertainties, and substantial challenges faced by the general population. Although assessing the effects of the COVID-19 pandemic is not a main component to this study, I would be remiss to not acknowledge this. Outside of their caregiver role, it is possible that stress response and general well-being could be impacted during this time. In the context of the caregiver role, parents may be experiencing greater or differential levels of stressors and concerns surrounding their child with ASD (particularly future planning, decisions regarding school/living, remote learning, child's stress response, etc.).

Satisfaction and Rewards for Parents of Adults with ASD

Thus far, the current paper has focused on one of the two parallel processes impacting psychological well-being, according to Lawton's (1991) two-factor model of caregiving appraisal: caregiver burdens resulting in negative affect. However, this lifelong caregiving process is not exclusively negative, and parents do endorse the other factor in Lawton's model: positive experiences and satisfaction (Hastings & Taunt, 2002). It is important to capture these positive appraisals, particularly as they may reduce negative experiences and stressors for parent caregivers. Overall, the benefits or rewards expressed by parents relate to their personal growth, as opposed to instrumental support. For example, in assessing rewarding aspects of caring for an adult child with mental illness in older adulthood, parents reported greater gratification from

carrying out parent caregiving duties and discovering about themselves than from daily instrumental support (e.g., household chores, preparing meals) from their child (Schwartz & Gidron, 2002). Whereas parents of adult children with ASD identified social exclusion due to their lifelong caregiving role, most also simultaneously acknowledged rewards from this role, including greater patience, changes in perspectives, and positive relationship changes with family and community members who also serve as advocates for individuals with ASD (Marsack & Perry, 2018). Although this enduring caregiver role proves stressful, parents can and do demonstrate resiliency.

Parents, particularly mothers, of children with developmental disabilities have shown comparable perceptions of inner strength and acceptance as a result of caregiving challenges (Krauss & Seltzer, 2000). Qualitative research specifically has highlighted the unique aspect of meaning in life for parents of children with disabilities. Initial frustrations and challenges in the beginnings of the caregiver role may take on new forms with the passing of time, as parents report a developed sense of meaning in life, emotional strength, and personal growth as a result of their experience with their child (Kausar et al., 2003). In a content analysis of books authored by parents of children with a range of disabilities (including ASD), simultaneous themes emerged regarding stress and demands, as well as greater life meaning and enrichment by means of parenting their child with a disability (Mullins, 1987). Despite ongoing caregiving challenges, mothers of an aging child with ASD find opportunities for personal growth and meaning in life (Greenberg et al., 2010). For example, Bayat (2007) identified specific resiliency processes in parents of children with ASD, including positive meaning making, greater family closeness, affirming strength and greater compassion, and procuring spiritual strength. Meaning in life has been associated with increased psychological health, physical health, longevity, adaptive coping,

and reduced stress (Hooker et al., 2018). Research suggests that those with a greater sense of meaning and purpose in life have increased self-efficacy in coping skills amidst stressors (Sherman & Simonton, 2012), particularly for individuals with low positive affect (Shrira et al., 2015). In other words, when experiencing low mood, meaning in life may serve as a source of strength for coping with stressful life events.

There is limited research examining ways in which concern and fear about children's futures and apprehensions surrounding lifelong parenting play a role in the well-being and adaptation for parents, particularly as they may vary by specific disability. For older parents caring for an adult with ID, a small thematic account of their experiences and thoughts of the future revealed a theme of "tolerating uncertainty" (Pryce et al., 2017). A mixed methods study on parents of children with ASD and Fetal Alcohol Spectrum Disorder (FASD) sheds light on prevailing hopefulness and resiliency amidst substantial lifelong worries in parents of those with ASD (Watson et al., 2013). Quantitatively, both groups of parents endorsed significant worry and fears for the future of their child. Although similar qualitative themes emerged from both groups of parents, including anxiety about future independence, concerns of educational ventures, and fear of harm, the qualitative presentation of hope was quite different across the two groups. Parents of children with ASD recognized their child's life as being harder than others, yet expressed hope in future possibilities, such as their ability to live independently, obtain an education and meaningful employment, and start a family. They also expressed hopefulness in community awareness and acceptance, an important contributor to their child's full inclusion in the future. Overall, the researchers (Watson et al., 2013) note the reciprocal nature of hope in parents of children with ASD, as evidenced by agency thinking (potential for positive and independent lives) and pathways thinking (acknowledging their role as parents to be active in

helping them attain those goals). Although not synonymous with meaning in life, we can see how this reciprocal nature of hope overlaps with such a concept, as it relates to purposefulness, goal directedness, and significance of existence.

Interaction of the Parent's Aging Process Within Caregiver Processes

It is important to understand how stressors, resources, perceived burdens and satisfactions, rewards, coping, and adaptation unfold over time through the lens of the aging framework for these aging parent caregivers. Some cross-sectional data suggest that certain aspects of well-being are lower for mothers of younger children compared to mothers of adolescents or adults (Magana & Smith, 2006; Singer, 2006). Other studies have indicated sustained levels of stress and well-being across age groups, but decreased levels of depression and anxiety for parents of adolescents or adults compared to young children (Pozo & Sarria, 2015). Beyond age differences, other studies of parents caring for a child with a disability have indicated associations among longer duration of care and greater well-being (Ha et al., 2008). There is some longitudinal support for this: over a 10 year period, anxiety improved while depressive symptoms remained stable in mothers of adolescents and adults with ASD (Barker et al., 2011). In a short-term longitudinal study of mothers of a child or adolescent with ASD, anxiety decreased during a year and a half time period (Lounds et al., 2007). Discrepancies exist, however, as increased age was not related to increased well-being in mothers, despite improvements in their child's symptoms and behavior problems (Pozo & Sarria, 2015). Further, in the Panini sandwich caregiver role (Abramson, 2015), parents experience the "press" of their own aging. However, gerontological theories suggest that with age come gains in well-being and happiness (Charles & Hong, 2016). Thus, the current study incorporates specific factors related

to aging and ways in which those factors influence parent caregiver's health-related quality of life in this lifelong caregiving process.

With cumulative experience, parent caregivers can improve coping skills and sense of well-being (Ha et al., 2008). These improvements may at least somewhat reflect the normative age-related shifts in emotional well-being and mood regulation for adults generally, irrespective of holding caregiver roles (Jorm et al., 2005). Carstensen's (1995) lifespan theory, socioemotional selectivity theory (SST), posits that motivations are guided by perception of limited time. Compared to younger adults who tend to focus on knowledge acquisition and information-related goals, older adults prioritize goals related to emotional meaningfulness as a result of increased recognition of time left to live. At around 50 years old, people begin to report limitations on future possibilities, and by around 60 years, there are increasing reports of shortened time perception (Strough et al., 2016). As time horizon decreases, focus shifts to fulfillment of meaningful goals and regulation of emotions (Carstensen, 2006). Focus on more emotionally salient goals increases selectiveness in social environments and relationships that provide the most emotional reward. Social networks decrease in size; however, they experience enhanced emotional closeness, quality, and satisfaction with close interpersonal relationships (English & Carstensen, 2014; Carstensen et al., 2003). Older adults generally report the highest levels of subjective well-being across adulthood, which is at least partly presumed to be a function of this process and abilities to regulate negative emotions (Charles & Carstensen, 2009). Other age-related differences include the "positivity effect"—greater attention, preference, and memory of more positive over negative information (Carstensen & Mikels, 2005).

Importantly, these patterns of shortened time perspective are not specific to chronological age, but instead the subjective temporal context. Studies have shown effects of perceived limited

time due to health status/illness rather than age (Carstensen & Fredrickson, 1998) and successful manipulations of future time perspective relative to emotional processing of facial expression (Kellough & Knight, 2012). Other psychological constructs, such as subjective age rather than chronological age, seem to contribute to future time perspective. Older adults who identify less strongly with their actual age group demonstrated higher scores on the future being perceived as “open” on a measure of future time perspective (Weiss & Lang, 2012). Emphasis is placed on the fact that an awareness of the finitude of life is nuanced and the subjective pace of time is not constant (Lu et al., 2018).

It is important to consider how this lifespan theory relates to aging parent caregivers of adults with ASD. Researchers note how other variables, such as life transitions, terminal illness, health behaviors, and risk taking can shift an individual’s future time perspective (Hicks et al., 2012). Research has yet to examine how lifelong caregiving may shift future time perspective, but I presume it to be a multi-faceted and complex influence on parent caregivers of an adult with ASD. Worries about the future for their child is a highlighted stressor for parent caregivers, to the extent that some parents express desire that their child’s death precede their own (Hare et al., 2004). Further, parents of children with ASD are encouraged early on to engage in appropriate care planning for the future (Van Bourgondien et al., 2014). It may be that these perpetual caregivers experience a shifted shortened time perspective, as they are faced with thoughts of their future living situation, independence, and their own mortality early on as a parent and consistently throughout their lives following the ASD diagnosis. On the other hand, despite substantial concern and stress about the future, many parents do not make explicit plans for the future (Van Bourgondien et al., 2014). This could be due to the daunting and emotionally taxing process itself (Heller & Caldwell, 2006), avoidance of their own mortality, or reluctance

to “let go” in order to protect their child (Morrell & Palmer, 2006) or to protect themselves as this may reduce sense of purpose or meaning in later life (Pryce et al., 2017), among countless other reasons. For parents that manage future thinking by engaging in avoidance, they may hold a prolonged future time perspective.

At this stage in life and through a lifetime of accumulated experiences, these parents may have enhanced coping and self-regulation skills, possibly decreasing their experiences of distress, or even improving emotional well-being. Previously noted resiliency and meaning making demonstrated by parents of children and adults with ASD support this notion, as parents may develop insight into their capabilities, self-knowledge, and adjust life priorities in ways that emphasize appreciation for even small accomplishments, as a result of working through lifelong caregiver challenges (Schwartz & Gidron, 2002). On the other hand, there is variability in the toll of caregiving: whereas some demonstrate adaptation and gains (or at least maintenance) in well-being, for others it may have a “wear and tear” effect (Orsmond et al., 2006). This enhanced emotional functioning may not be the case for aging perpetual caregivers, as they have faced chronic stress, fatigue, and limitations of social support. While they continue to serve as their grown child’s caregiver, this may detract from the need to care for themselves as they age, possibly compromising their own well-being.

A final highlighted importance of SST for aging parents of children with ASD is social relationships. Due to caregiving demands, parents endorse lifelong social impediments (loss of quality time with friends/family, exclusion, restricted social lives). Thus, they may have already involuntarily engaged in this selection process early on, but maybe not necessarily as a function of fulfilling emotionally salient goals. Maintenance of the caregiving role at this stage in life may also hinder time, energy, and means for greater emotional connection of existing relationships.

Of the studies found in the ASD caregiving literature focusing on the under-researched population of aging parents (e.g., Hines et al., 2014; Piazza et al., 2014; Pozo & Sarria, 2015; Marsack & Perry, 2018), components of the aging process and lifespan considerations are mentioned, but lack incorporation of lifespan theory into the conceptual framework. The current study aims to begin to bridge this gap by incorporating aspects of SST into the Double ABCX conceptual model to guide the research.

Conceptual Framework

Commonly, the Transactional Model of Stress and Coping (TSC; Lazarus & Folkman, 1984) offers a fitting theoretical framework for assessing family caregiver outcomes. In this model, appraisal (cognitive attribution to stressor) and coping style (problem-focused, emotion-focused; approach, avoidant) are suggested to mediate the consequences of stressors. Lazarus and Folkman (1984) noted the coping process arises from interactions of social environment, resources, and individual characteristics that influence appraisal of stress. McCubbin and Patterson (1983) developed the Double ABCX Model of Family Adaptation, an expansion of Hill's original ABCX family crisis model (1949; 1958) that applies Lazarus and Folkman's (1984) theory to families facing stress. Such models of adaptation within families have proven useful to identify and organize variables relevant to the continual dynamic adaptation process of family members throughout the developmental stages of the child with ASD (Manning et al., 2011). The original ABCX Model consists of a crisis-precipitating event/stressor (A) that interacts with the family's stressor-meeting resources (B) and with the subjective definition the family applies to the event (C), which produces the family crisis (X). The Double ABCX Model adds "post-crisis" variables with the intent to conceptualize and describe life stressors, resources, and appraisal over time, as well as coping strategies (Manning et al., 2011). This revised model

focuses on five components: pileup of stressors (ongoing and cumulative resulting from the initial stressor; aA), social and psychological resources/support (bB), appraisal/assigned meaning of factor aA and factor bB (cC), and coping (BC), which is considered an interaction between resources and appraisals. Adaptation (xX) can be a positive or negative outcome of interactions among the variables (McCubbin & Patterson, 1983). Previous studies have measured adaptation as psychological distress (Bristol, 1987; Pakenham et al., 2005; Paynter et al., 2013), well-being (Pozo et al., 2014), parenting stress (McStay et al., 2014; Manning et al., 2011), family quality of life (McStay et al., 2014; Pozo et al., 2014), caregiver burden (Stuart & McGrew, 2009), and marital adjustment (Bristol, 1987), among others.

The Double ABCX Model has proven useful to examine factors of adaptation for families of children with ASD (Bristol 1987; McStay et al., 2014; Pozo et al., 2014; Pakenham et al., 2005; Manning et al., 2011; Paynter et al., 2013; Stuart & McGrew, 2009). Although the current study does not focus on the family unit, this model was chosen because it captures and expands upon elements from the TSC in the context of ongoing adaptation to the caregiver role. Other researchers (e.g., Pakenham et al., 2005) have effectively used this model for assessing maternal adjustment in particular.

Purpose of the Study

The proposed study adopted the Double ABCX Model as a framework to examine health-related quality of life and meaning in life in aging parents of adults with ASD who are currently attending college or university. The study contributes novelties to this growing literature. First, literature on parents of adults with ASD that incorporates or acknowledges aspects related to lifespan/aging theories is sparse. For example, no research to date has assessed future time perspective in parents of those with ASD, which is an important contribution to existing research

given the lifelong circumstances faced by these parents, and the implications of future time perspective for emotional well-being and meaningful goals as noted previously. In addition, attempts to identify appropriate interventions and supports for parents of adults without examining the interrelations of the enduring caregiver role and specifics of the aging process are problematic. Thus, the study also explores and initiates development of a novel measure, specifically for parents of adults with ASD, that places an emphasis on the lifespan.

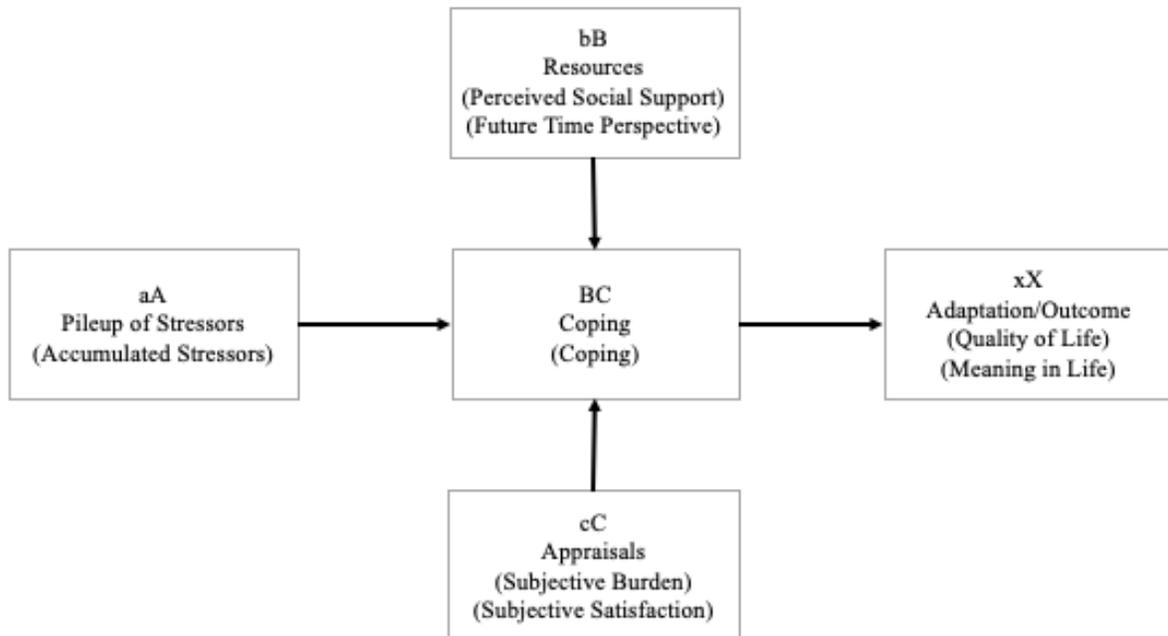
The primary proposed focus of the study was to use quantitative methods to examine the effects of pileup of stressors (aA; accumulated stressors), resources (bB; perceived social support, future time perception), appraisals (cC; subjective burden and satisfaction), and coping (BC; coping strategies) on adaptation (xX; health-related quality of life, meaning in life) for aging parent caregivers of adults with ASD, specifically with parents of young adults currently attending college or postsecondary school, as the services, needs, and experiences for both are nuanced due to aspects of functional status. Given past research noting parents experiencing objective, accumulated stressors over the course of caregiving since their child's initial diagnosis (Dudley et al., 2019; Eaves & Ho, 2008; Heller & Caldwell, 2006; Howlin, 2004; Marsack & Perry, 2018; Palmer, 2006; Smith et al., 2010; Van Bourgondien et al., 2014; Volkmar et al., 2014), stressor pileup was conceptualized as parent's accumulated stressors throughout their child's development. Resources in the proposed model consisted of perceptions of social support and future time perspective. Across general populations, the perception of accessibility of emotional supports is more strongly associated with physical and emotional well-being than is the amount of received support (Haber et al., 2007). Additionally, time perception may be a psychological resource that shapes how parents respond to stress and coping. In terms of appraisal, caregivers often simultaneously express both positive and negative appraisals of

caregiving (Lawton et al., 1991). Thus, this was measured by subjective burden and satisfaction, applying the two parallel processes of caregiving appraisal. In considering interactions amongst perceived social support, future time perspective, and subjective burden and satisfaction, coping strategies were proposed to be examined, including approach and avoidant coping. Avoidant coping strategies (e.g., venting, denial, distraction), although possibly appropriate initial reactions to stress, are not as adaptive compared to approach coping strategies (e.g., seeking support, planning, positive reappraisal) in the long-term when facing chronic stressors, such as perpetual caregiving (Carver, 1997; Pakenham, 1999). Lastly, as previous research shows the poor physical and mental health for parents of children and adults with ASD, the outcome of interest in the study was parent's health-related quality of life. Additionally, given the resiliency research suggesting enhanced or newfound meaning in life as a result of working through lifelong caregiver challenges, as well as the lifespan research indicating the shift toward a more meaningful and emotionally salient life, meaning in life was also examined as a parent outcome. It was hypothesized that stressor pileup (aA) has direct (negative) effects on resources (bB), appraisal (cC), and coping (BC). Both resources (bB) and appraisal (cC) were hypothesized to have direct (positive) effects on coping (BC) and adaptation (xX). Coping (BC) was hypothesized to have a direct (positive) effect on adaptation (xX) (see Figure 1).

However, given the small size of the final sample, proposed quantitative analyses were not able to be conducted, and the focus of the study shifted to qualitative analyses and exploration, in line with the previously identified goal of focusing on lifespan factors. Specifically, qualitative data on parent experiences and stressors across their child's development highlights unique problems and facilitates development and further examination of a measure accumulated stressors in parents.

Figure 1

Applied Double ABCX Model for Aging Parents of Adults with ASD



METHOD

Participants and Procedure

Phase 1

The goal of Phase 1 was to administer the developed measure for the current study (Accumulated Stressors Scale) and complete brief cognitive interviews with parents of adults with ASD. Cognitive interviews most commonly involve administration of the drafted survey measure and gathering further information through verbal discourse about the measure responses (Beatty & Willis, 2007). This process allowed for greater evaluation and modification of questions to ensure accurate reflections of their experience and to fit the objectives for the current study in a feasible manner. Phase 1 involved recruiting a small sample (goal of five to ten) of parents who previously had a child enrolled in an ASD college support program within the past three years. Sampling former parents of the program within the past three years was presumed to elicit objective perspective and feedback from parents who have already gone through this transition period into young adulthood with their child. Parents of former students who previously consented to be contacted for future research studies were contacted via email with IRB documentation and a Qualtrics link for those interested in participating to provide contact information, scheduling preferences, and consent. Parents who indicated interest were contacted by the primary investigator within three days of completing the survey. Parents were required to be 40 years or older, with the ability to read English and have access to internet. Participation was limited to only one parent per child. Individual interviews were completed over the phone or via Zoom depending on participant preference. All participants provided verbal

consent prior to beginning audio recordings. Interviews consisted of initial brief demographic questions about the parent and their child, followed by completion of the drafted 16-item Accumulated Stressors Scale (See Appendix A), intended to measure parent stressors over the course of caregiving for a child with ASD from childhood through young adulthood. Parents were instructed to read through the measure aloud and provide responses aloud. Parents then responded to specific questions and shared their thoughts about the measure after completion, but were encouraged to share any thoughts or questions while responding if they desired to do so. Thus, the cognitive interview method was considered to be a hybrid approach, including probing and think-aloud techniques combined, which has been suggested by survey developers (Beatty & Willis, 2007). Cognitive interviews were semi-structured (See Appendix B). The primary investigator included comprehension, paraphrasing, specific, and general cognitive probes (Willis & Artino, 2013) throughout the interview. A total of 6 interviews were completed and transcribed. All parents identified their child was originally diagnosed with Asperger Syndrome, now classified under autism spectrum disorder. Table 1 includes demographics for the 6 participants. Feedback from parents in Phase 1 was used to improve the measure prior to completion of Phase 2.

Table 1*Demographics for Phase 1 Interviews (N = 6)*

	n (%)	M (Range)
Parent		
Age		57.2 (50 – 62)
Race		
White	5 (83.3%)	
White Hispanic	1 (16.6%)	
Gender Identity		
Female	4 (66.6%)	
Male	2 (33.3%)	
Child		
Age		24.6 (22 – 26)
Race		
White	6 (100%)	
Gender Identity		
Male	6 (100%)	
Age of Diagnosis		6.5 (4 – 9)
Other Mental Health Diagnoses		
ADHD	2 (33.3%)	
Anxiety (GAD or unspecified)	4 (66.6%)	
Depression (unspecified)	2 (33.3%)	
OCD	1 (16.6%)	
None	2 (33.3%)	

Phase 2

Phase 2 consisted of dissemination of a web-based (Qualtrics) survey including all measures outlined below. In order to sample parents of individuals with HFA in the transition period of young adulthood, recruitment was completed through college and post-secondary ASD support and transition programs across the U.S. by using the comprehensive list of programs by state provided by the professional organization, College Autism Spectrum (*College Programs,*

n.d.). Additional in-depth internet searches were conducted for college transition and support programs potentially not listed. Specific searches were also completed for historically black colleges and universities (HBCUs); however, I was unable to find any HBCUs with this type of program. Program inclusion criteria consisted of a required formal diagnosis of an autism spectrum disorder (e.g., autism, ASD, Asperger syndrome, Pervasive Developmental Disorder-Not Otherwise Specified; PDD-NOS) for each student, and for students to be fully matriculated. Initially, programs that indicated serving students with a variety of diagnoses that may impact academic functioning (e.g., ADHD, LD, “other neurodiversities”) were excluded from the study. However, to increase sample pool, these programs were included; screening questions addressed and excluded participants who did not have a child with a formal ASD diagnosis. Training and certificate programs were excluded. In total, 66 programs were contacted via email two times for an initial request and follow-up (See Appendix C). All program directors (or other indicated contacts) were emailed a description of the study, IRB documentation, and a request to disseminate the survey link to parents of students enrolled in the program. One program director responded stating they do not send any research requests to parents. Two other program directors responded specifically stating they were unable to share the study due to the high volume of research requests they receive. Directors reported that they limit the number of research studies because they lack staff resources to devote time to determining which studies to share and they also do not want to overwhelm individuals in the program. Overall, I received five email responses from directors confirming dissemination of the survey to parents. One program director specifically shared sending the survey to approximately 70 recipients.

Parents from these programs who were interested in participating were required to be 40 years or older, with the ability to read English, have access to internet, and have one adult child

18 years or older with a formal diagnosis of ASD currently enrolled in college, university, or post-secondary education. Participation was limited to only one parent per child. Given the ongoing COVID-19 pandemic, parents whose child had been enrolled in the program in prior years, but was not currently enrolled strictly due to the pandemic, were also able to participate, although there were no participants of this nature. Parents responded to screening questions on the inclusion criteria above prior to moving forward with the survey. In total, there were 33 parent responses. Of the 33 responses, four parents were screened out before survey completion, as two parents did not meet age criteria, one parent did not meet age criteria regarding their child with ASD, and one parent did not consent. In addition, one respondent did not complete any measures after completing screening questions. Thus, the final sample consisted of 28 parents from a total of five different support/transition programs. Of the five programs I received email confirmations from regarding survey dissemination, parents from four programs participated in the survey. There was one program that did not send email confirmation of survey dissemination that did end up sharing the study with parents, which led to a total of five programs. Programs are not named in order to protect participant confidentiality, but in order to get a sense of responses by program, the highest number of participants in one program was $n = 10$ (35.7%), another program of $n = 7$ (25%), followed by another program of $n = 6$ (21.4%), and the final two programs of $n = 3$ (10.7%), and $n = 2$ (7.1%). Table 2 includes demographics for the survey participants in Phase 2.

Table 2*Demographics for Phase 2 Participants (N = 28)*

	n (%)	M (Range)
Parent		
Age		
40 – 49	6 (21.4%)	
50 – 59	21 (75%)	
60 – 69	1 (3.6%)	
Race		
White	26 (92.9%)	
Black	1 (3.6%)	
Asian/Asian American	1 (3.6%)	
Gender Identity		
Female	24 (85.7%)	
Male	4 (14.3%)	
Parent-Child Relationship		
Biological mother	24 (85.7%)	
Biological father	4 (14.3%)	
Sexual Orientation		
Heterosexual	27 (96.4%)	
Demisexual	1 (3.6%)	
Marital Status		
Married	25 (89.3%)	
Divorced/Separated	2 (7.1%)	
Single	1 (3.6%)	
Education		
Some college, no degree	1 (3.6%)	
Bachelor's degree	11 (39.3%)	
Graduate/professional degree	16 (57.1%)	
Employment Status		
Employed full time	17 (60.7%)	
Employed part time	6 (21.4%)	
Homemaker	3 (10.7%)	
Retired	2 (7.1%)	
Number of Children (including ASD child)		2.39 (1 – 5)
Income Adequacy		
Not at all difficult	19 (67.9%)	1.36 (scale range 1 – 5)

Somewhat difficult	8 (28.6%)
Difficult or can barely get by	1 (3.6%)
Current State Residence	
Illinois	11 (39.3%)
Alabama	4 (14.3%)
Ohio	3 (10.7%)
Georgia	2 (7.1%)
Indiana	2 (7.1%)
Kentucky	2 (7.1%)
Missouri	2 (7.1%)
Pennsylvania	1 (3.6%)

Child

Age		20.39 (19 – 23)
Race		
White	26 (92.9%)	
Black	1 (3.6%)	
Asian/Asian American	1 (3.6%)	
Gender Identity		
Female	4 (14.3%)	
Male	24 (85.7%)	
Sexual Orientation		
Heterosexual	23 (82.1%)	
Bisexual	1 (3.6%)	
Don't know/prefer not to respond	4 (14.3%)	
Primary Diagnosis		
Autism Spectrum Disorder	17 (60.7%)	
Asperger Syndrome	9 (32.1%)	
PDD-NOS	2 (7.1%)	
Age of Diagnosis		8 (2 – 18)
Other Mental Health Diagnoses		
ADHD	13 (46.4%)	
Anxiety (unspecified)	12 (42.8%)	
Depression (unspecified)	6 (21.4%)	
OCD	6 (21.4%)	
Sensory processing disorder	2 (7.1%)	
PTSD	1 (3.6%)	

ODD	1 (3.6%)	
Tourettes	1 (3.6%)	
Apraxia	1 (3.6%)	
None	7 (25%)	
Psychiatric Medications Prescribed		
Yes	17 (60.7%)	
No	11 (39.3%)	
ASD Program Cost Per Semester		\$2821.43 (\$0 - \$8,000)
Academic Year		
Freshman	5 (17.9%)	
Sophomore	11 (39.3%)	
Junior	8 (28.6%)	
Senior	4 (14.3%)	
Residence		
Dorm room alone	13 (46.4%)	
Dorm room with roommates	3 (10.7%)	
Off campus apt/house alone	3 (10.7%)	
Off campus apt/house with roommates	1 (3.6%)	
On campus apt with roommates	1 (3.6%)	
In household with parent	7 (25%)	
ASD Severity		1.16 (scale range 1 – 3)

Measures

The primary constructs utilized for the survey were accumulated stressors, perceived social support, future time perspective, caregiver appraisal (burden and satisfaction), coping, meaning in life, and health-related quality of life. Relevant demographic variables were collected, as well as two open-ended questions related to the accumulated stressors scale and two open-ended questions related to personal and caregiving concerns related to COVID-19. Of note, although composites and indicated subscales were computed for each variable, analyses of internal consistency were not completed due to the small sample size.

Phase 1

Accumulated Stressors was developed for the study to measure parent's objective accumulated stressors related to their lifelong caregiving role for their child with ASD. The items were developed through an extensive literature review, and fall within the domains of parent stressors mentioned previously (future planning, self-care/social support, transition into young adulthood, services/unmet needs). Each domain consists of four items, totaling 16 items. The originally proposed measure was dichotomous (yes/no) for parents to endorse items they have experienced, as opposed to appraisals of the experiences as stressful. In addition, the measure instructed parents to answer items considering experiences they have had at any point in their child's development (from ASD diagnosis to present) for domains of future planning and self-care/social support, and answer items considering experiences only since their child entered adulthood (age 18 to present) for domains of young adulthood transition and services/unmet needs. After receiving evaluation from three PhD-level autism experts regarding minor changes in wording, formatting, and content, Phase 1 (administration and cognitive interviews) was completed with the six parents (See Appendix A and B).

Phase 2

The *Accumulated Stressors* measure was adapted to reflect feedback from Phase 1. Appropriate edits and IRB modifications were completed before disseminating the national survey (See Appendix D). This was, of course, an exploratory aspect of the study, and limitations exist by not conducting all phases of scale development and validation. Nonetheless, both phases of this study begin to provide data for preliminary evaluation of the scale. Given the sample size and subsequent limited interpretability with the data obtained, counts were computed for experiences and stressors endorsed. Specifically, considering parent feedback in Phase 1

regarding proposed timeframe of the questions (see Table 5), for items 1-8 a count was computed for experienced and stressors endorsed in childhood only (before age 18). For all items (1-16) a count was computed for experiences and stressors endorsed in adulthood only (age 18 and older). Lastly, a count was computed again for all items, counting any endorsement on items 1-8 (childhood only, adulthood only, both childhood and adulthood) plus endorsements on items 9-16 (which only focused on adulthood). Table 3 shares the frequencies of items endorsed as experiences parents have had at different stages in life, followed by appraisal of that experience as a stressor or not at different stages of life.

The Medical Outcomes Study (MOS) Social Support Survey (Sherbourne & Stewart, 1991) is a brief multidimensional measure that was utilized to measure *perceived social support*. The survey's 18 items construct an overall social support index, as well as four dimensional scales: (1) *Emotional/informational support* contains eight items focusing on expression of positive affect, empathetic understanding, encouragement to express feelings; and offering advice, information, guidance or feedback, (2) *Tangible support* contains four items focusing on providing material aid or behavioral assistance, (3) *Positive social interaction* contains three items focusing on availability of others to do fun things, and (4) *Affectionate support* contains three items focusing on expressions of love and affection. Respondents rate how often each kind of support is available if they needed it, on a scale from 1 (none of the time) to 5 (all of the time). As opposed to frequency of contact or structural measures of social support, this measure taps important aging-related processes and aspects of the SST framework: quality/meaningful relationships and selectiveness in those relationships. The composite perceived social support variable and component subscales were computed by averaging across items.

Future time perspective was measured using the multidimensional Future Time Perspective Scale (Brothers et al., 2014). Given that lifespan developmental theory considers most constructs as multidimensional and also multidirectional (Baltes et al., 2006), this brief 12-item scale was chosen as it measures three dimensions: *future as open*, *future as limited*, and *future as ambiguous*. Items are answered on a scale ranging from 1 (strongly disagree) to 5 (strongly agree). The three scales were computed by summing respective items. The measure has been shown to be reliable and valid. Evaluation of the measure consists of participants ranging from 18 to 93 years old, with results suggesting the three dimensions are assessed comparably in young, middle-aged, and older adults (Brothers et al., 2014). Limitations of the measure do exist, as the Brothers' and colleagues (2014) sample ($n = 625$) was largely Caucasian, well-educated, and generally healthy. There have been few other assessments of the measure to test psychometric properties in other samples. Nonetheless, this scale was considered more appropriate for the study compared to some scales that are one-dimensional and demonstrate a lack of psychometric evidence (Future Time Perspective; Carstensen & Lang, 1996), or other scales that were validated primarily in samples of adolescents and young adults (Zimbardo's Time Perspective Inventory; Zimbardo & Boyd, 1999).

The Revised Caregiver Appraisal Scales (Lawton et al., 2000) was used to measure caregiver *burden* (nine items) and *satisfaction* (six items), which are rated on a 1 (disagree a lot/never) to 5 (agree a lot/nearly always) scale. The composite burden and satisfaction variables were computed by summing all respective items. Previous studies with parents of adults with diverse disabilities including ASD report good internal consistency of the burden subscale ($\alpha = 0.87$; Pruchno & McMullen, 2004; $\alpha = 0.92$; Weiss et al., 2016). In terms of the satisfaction subscale, previous studies have used older versions of the scale (Lawton et al., 1982), which do

report good internal consistency in samples of parents of adults with ASD and a variety of developmental disabilities ($\alpha = 0.78$; Burke & Heller, 2016; Miltiades & Pruchno, 2002).

Coping was assessed using the Brief Coping Orientation of Problems Experienced (Brief-COPE; Carver, 1997). The 28 items are rated from 1 = *I haven't been doing this* to 4 = *I've been doing this a lot*. There are 14 subscales that represent a broad dimension of coping strategies. This is a shortened version of the 60-item COPE Scale (Carver et al., 1989), based on various theoretical models of coping. Succeeding factor analysis of the measure used with patients with heart failure demonstrated two main structures of *avoidant coping* and *approach coping* (Eisenberg et al., 2012), of which two subscales (humor and religion) do not load on either of the two factors and are standalone subscales. Research on parents of children with ASD has used the measure, with some reducing the number of coping strategies using principal component factor analysis, such as factors of active avoidance coping ($\alpha = 0.78$), problem-focused coping ($\alpha = 0.82$), positive coping ($\alpha = 0.68$), and religious/denial coping ($\alpha = 0.73$) (Hastings et al., 2005b), and others (Pozo et al., 2014) reducing the scale to two factors, problem-focused (active/approach) coping ($\alpha = 0.78$) and avoidance coping ($\alpha = 0.71$). For the current study, the two main factor structures of approach and avoidant coping were maintained by summing items for each factor as indicated by past research (Pozo et al., 2014; Eisenberg et al., 2012).

One of the outcome variables, *meaning in life*, was measured with the Meaning in Life Questionnaire (MLQ; Steger et al., 2006). This is a 10-item measure of the *presence of*, and *search for*, meaning in life. Items are answered on a scale ranging from 1 (absolutely untrue) to 7 (absolutely true). After reverse coding one item, the scales were computed by summing respective five items per scale. MLQ scores demonstrate good internal consistency (alphas typically range from low .80 to low .90 for both subscales; Schulenberg et al., 2011), temporal

stability, factor structure, and convergent and discriminant validity of the subscales across time and informants. Although this measure has not been utilized in many samples of middle-aged adults or parents, it offers better psychometrics than other commonly used measures (Purpose in Life Test; Crumbaugh & Maholick, 1964; Life Regard Index; Battista & Almond, 1973), including no item overlap with distress measures, stable factor structure, better discriminant validity, and a briefer format.

The other targeted outcome variable, *health-related quality of life (HRQOL)*, was measured with the 36-item Short Form Survey (SF-36; Ware & Sherbourne, 1992), which some note as the “gold standard” measure of general HRQOL as it is well validated in many groups. This measures eight different health concepts, including physical function, role limitation because of physical problems, bodily pain, general health perceptions, social function, emotional well-being, role limitation because of emotional problems, and energy/fatigue. Scoring for the current study followed processes outlined in the user’s manual (Ware et al., 1994), first recoding all items on a 0 to 100 range. Respective items were averaged per each of the eight subscales listed above. In order to compute the two summary domains commonly generated from this measure (physical component summary; PCS, mental component summary; MCS) the eight subscales were standardized and aggregated with different weights. The component scores were then transformed to norm-based scoring. Mean scores for the PCS and MCS for the general population are both 50. In a study of parents of children with ASD (Johnson et al., 2011). Cronbach’s alpha reliability coefficients for subscales ranged from .81 to .93.

Parents completed a demographic questionnaire for themselves and their child with ASD (see Table 2). Although it is common and useful to verify the individual meets criteria for ASD and obtain data on symptom severity in research (e.g., Childhood Autism Spectrum Test; CAST,

Scales of Independent Behaviors-Revised; SIB-R, Aberrant Behavior Checklist; ABC, etc.), utilizing support and transition programs that require this formal diagnosis for enrollment in the program minimized the necessity for parents to complete such an assessment in the current study. Additionally, standardized measures of other-reports (i.e., parents) for populations of HFA are difficult to come by. In order to obtain simple information regarding symptom severity/problem behaviors, parents responded to two items regarding their child’s current severity on social communication challenges and restricted/repetitive behaviors, based on DSM-5 severity level/required support specifiers (American Psychiatric Association, 2013). One is indicated as the lowest level of severity/required support and 3 the highest level of severity/required support. The two items were averaged.

After completion of all survey measures and demographics, parents were asked two quantitative questions focusing on the COVID-19 pandemic: “How much has the COVID-19 pandemic affected you?” and “How much has the COVID-19 pandemic affected your caregiving/concerns about your child with ASD?” with responses on a scale from 1 (not at all) to 5 (extremely). It was deemed important to gather information to consider the ways in which a global pandemic is affecting participants well-being generally, but also within their role of parents to an adult with ASD at a time such as this.

Table 3

Frequencies for Accumulated Experiences vs. Appraised Stressors

Items 1 – 8 (ever experienced from childhood to present)			
<i>Considered who will provide care when you are no longer able to</i>			
Experience	n (%)	Stressor	n (%)
Childhood only	4 (14.3%)	Childhood only	7 (25%)
Adulthood only	3 (10.7%)	Adulthood only	2 (7.1%)
Both childhood & adulthood	17 (60.7%)	Both childhood & adulthood	14 (50%)

Neither childhood nor adulthood	4 (14.3%)	Neither childhood nor adulthood	5 (17.9%)
<i>Considered your child's future in terms of residence, employment, & general lifestyle</i>			
Childhood only	1 (3.6%)	Childhood only	1 (3.6%)
Adulthood only	5 (17.9%)	Adulthood only	5 (17.9%)
Both childhood & adulthood	22 (78.6%)	Both childhood & adulthood	17 (60.7%)
Neither childhood nor adulthood	0	Neither childhood nor adulthood	1 (3.6%)
<i>Actively engaged in future planning decisions (including but not limited to guardianship, letter of intent, financial planning, etc.)</i>			
Childhood only	1 (3.6%)	Childhood only	3 (10.7%)
Adulthood only	4 (14.3%)	Adulthood only	5 (17.9%)
Both childhood & adulthood	12 (42.9%)	Both childhood & adulthood	9 (32.1%)
Neither childhood nor adulthood	11 (39.3%)	Neither childhood nor adulthood	11 (39.3%)
<i>Lacked adequate or understandable information about future planning</i>			
Childhood only	5 (17.9%)	Childhood only	4 (14.3%)
Adulthood only	5 (17.9%)	Adulthood only	4 (14.3%)
Both childhood & adulthood	7 (25%)	Both childhood & adulthood	7 (25%)
Neither childhood nor adulthood	11 (39.3%)	Neither childhood nor adulthood	13 (46.4%)
<i>Involvement in your own personal activities/events less than desired due to aspects of caregiving (e.g., hobbies, clubs)</i>			
Childhood only	9 (32.1%)	Childhood only	7 (25%)
Adulthood only	0	Adulthood only	0
Both childhood & adulthood	9 (32.1%)	Both childhood & adulthood	7 (25%)
Neither childhood nor adulthood	10 (35.7%)	Neither childhood nor adulthood	14 (50%)
<i>Unable to obtain relief from aspects of caregiving</i>			
Childhood only	11 (39.3%)	Childhood only	11 (39.3%)
Adulthood only	2 (7.1%)	Adulthood only	2 (7.1%)
Both childhood & adulthood	2 (7.1%)	Both childhood & adulthood	2 (7.1%)
Neither childhood nor adulthood	13 (46.4%)	Neither childhood nor adulthood	13 (46.4%)
<i>Time spent with family and/or friends less than desired due to aspects of caregiving</i>			
Childhood only	8 (28.6%)	Childhood only	7 (25%)
Adulthood only	0	Adulthood only	0
Both childhood & adulthood	6 (21.4%)	Both childhood & adulthood	5 (17.9%)
Neither childhood nor adulthood	14 (50%)	Neither childhood nor adulthood	15 (53.6%)

<i>Social isolation, or exclusion, or loss of social supports</i>			
Childhood only	7 (25%)	Childhood only	8 (28.6%)
Adulthood only	0	Adulthood only	1 (3.6%)
Both childhood & adulthood	8 (28.6%)	Both childhood & adulthood	6 (21.4%)
Neither childhood nor adulthood	13 (46.4%)	Neither childhood nor adulthood	13 (46.4%)
Items 9 – 16 (experienced from age 18 to present)			
<i>Navigating new systems/services for adults (e.g., vocational rehab, supported employment, mental health, disability services, other agencies)</i>			
Experience	n (%)	Stressor	n (%)
Yes	19 (67.9%)	Yes	15 (53.6%)
No	9 (32.1%)	No	13 (46.4%)
<i>Loss of entitlements, services, or resources</i>			
Yes	7 (25%)	Yes	6 (21.4%)
No	21 (75%)	No	22 (78.6%)
<i>Balancing their autonomy and my involvement/support</i>			
Yes	24 (85.7%)	Yes	22 (78.6%)
No	4 (14.3%)	No	6 (21.4%)
<i>Determining appropriate living situation</i>			
Yes	16 (57.1%)	Yes	12 (42.9%)
No	12 (42.9%)	No	16 (57.1%)
<i>Appropriate adult ASD services and/or interventions are not available</i>			
Yes	8 (28.6%)	Yes	4 (14.3%)
No	20 (71.4%)	No	24 (85.7%)
<i>More services for my adult are needed (including but not limited to employment, mental health, life skills services, day programs, etc.)</i>			
Yes	11 (39.3%)	Yes	9 (32.1%)
No	17 (60.7%)	No	19 (67.9%)
<i>Unable to obtain desired services due to adult's level of functioning</i>			
Yes	10 (35.7%)	Yes	9 (32.1%)
No	18 (64.3%)	No	19 (67.9%)
<i>Lack of social outlets for my adult child</i>			
Yes	18 (64.3%)	Yes	15 (53.6%)
No	10 (35.7%)	No	13 (46.4%)

Statistical Analyses

Structural equation modeling (SEM) was proposed for the current study in order to examine simultaneous relationships among stressor pileup, resources, appraisals, coping, health-related quality of life, and meaning in life in the proposed Double ABCX Model. However, given the resulting small sample size ($N=28$), SEM or other methods (ordinary least squares regression) were not feasible to conduct due to low power (Tabachnick & Fidell, 2013; Boomsma, 1982, 1985; Kline, 2015). Thus, analyses focus on Phase 1 and Phase 2 of the study with a particular focus on qualitative data. See Table 4 for resulting descriptives of proposed primary study variables.

Phase 1

Quantitative measures weren't distributed during Phase 1; thus, no statistical analyses were conducted. Although not originally a primary focus of the study, individual interviews provided novel and meaningful aspects necessitating further focus. The general goal of cognitive interview analysis is to identify problems participants had within potential different domains, and although some form of coding may be used for summation purposes, others have identified drawbacks of coding as time-consuming and overly reductive, hindering the level of information needed in order to actually edit and repair questions (Willis, 2005; Collins, 2007). Yet others (Willis & Artino, 2013) note the importance of coding by combining notes to each assessed item, seeking common themes, and identifying important aspects of the survey necessitating repair as a result. Given the variable reports in analysis for semi-structured cognitive interviews, thematic analysis was used due to the flexibility it provides, particularly given that it only serves as a method of analysis; one does not need to adhere to particular data collection methods, epistemological frameworks or theoretical perspectives. Since the cognitive interviews were

originally proposed as a small exploratory portion of the study these aspects of were not of primary focus. In addition, thematic analysis can be used with a variety of types of data and sizes of datasets (Braun & Clarke, 2013). Thus, thematic analysis was considered most appropriate to maintain the integrity of the research.

Thematic analysis involves six steps (Braun & Clarke, 2013), which are outlined below. The first step is transcription. Following this is the process of “familiarizing” oneself with the data, which involved actively reading and engaging with the data and using questions to better consider the meaning behind the data (e.g., “How does the parent make sense of their experiences?,” “In what different ways do they make sense of the topic discussed?,” and “What kind of world is revealed through their account?”). After this, the third step of generating initial codes was completed by engaging in selective coding for the purpose of data reduction. The particular type of data I was interested in selecting out was specific to instances of participant expressions of disparate experiences or perceptions of measure items including content, formatting, or wording. After completing the coding process using data-derived codes, they were collected and themes were identified by continually collating codes and aggregating them by conceptual similarity. Themes and subsequent codes were then reviewed and defined.

Phase 2

For Phase 2 analyses, statistical analyses were limited to bivariate correlations, again due to sample size, which were completed with SPSS version 28. Bivariate correlations were analyzed based on hypothesized associations amongst variables in the originally proposed Double ABCX model. These bivariate correlations are supplemented by rich qualitative data focused on two areas: 1) lifespan considerations and adaptations of the stress process over time for parents of children with ASD, and 2) the alterations in stress by the complex multilayered

aspects of a pandemic that directly target core features of ASD. Due to the unexpected developments with data collection, the rigorous and accelerated data reduction (RADaR) technique was used (Watkins, 2017) in order to utilize and engage in qualitative analyses that contributes meaningful data (while acknowledging limitations). This process highlights step-wise systematic analysis that facilitates a more accelerated pace in data reduction and subsequent manageable data dispersion. This was completed in five steps; first, ensuring that all data transcripts were formatted similarly, and placing formatted transcripts into all-inclusive phase 1 data table where data is further reviewed. Following review of the all-inclusive data table and note-taking, an overarching research question was created on the data table, which was continually referred back to throughout the coding process. The third step involved creating a phase 2 data table, which removed any content that was not of primary interest or not relevant to the research question. During this step, specific points of text were highlighted and rows were coded using open codes. This was completed as an iterative process by continually creating shorter and highly focused data tables by removing irrelevant data and with each phase generating more focused codes. By the fourth phase of this iterative process, final themes were identified and major codes and quotes that helped to define those themes remained in the final data table. Thus, overall, this method is largely similar to processes of thematic analyses noted above, however, given the larger amount of qualitative data for Phase 2, this specific RADaR technique was utilized to more efficiently organize, reduce, and analyze the data using more Microsoft Excel. Although it is particularly advantageous to complete this process in a team, it is also noted to be an individual approach to rigorous qualitative data coding/analysis (Watkins, 2017).

Table 4*Descriptives of Proposed Primary Study Variables (N = 28)*

	M (SD)	Range
Perceived Social Support	3.49 (1.08)	1.28 – 5
Future Time Perspective		
Open	14.64 (3.16)	4 – 20
Limited	14.32 (2.65)	8 – 20
Ambiguous	10.82 (2.58)	6 – 17
Burden	20.14 (7.45)	9 – 35
Satisfaction	21.89 (4.13)	17 – 30
Avoidant Coping	18.89 (4.04)	12 – 27
Approach Coping	31.07 (6.21)	20 – 45
Physical Health	51.15 (7.89)	31.16 – 62.02
Mental Health	46.47 (8.64)	27.08 – 59.64
Meaning in Life Presence	26.71 (6.19)	11 – 35
Meaning in Life Search	20.78 (6.24)	9 – 32
Parent Experiences: Childhood Only	1.64 (1.42)	0 – 8
Parent Stressors: Childhood Only	1.71 (1.51)	0 – 8
Parent Experiences: Adulthood Only	4.71 (2.34)	0 – 16
Parent Stressors: Adulthood Only	3.96 (2.31)	0 – 16
Parent Experiences: Across Lifespan	9.32 (3.52)	0 – 16
Parent Stressors: Across Lifespan	8.07 (3.84)	0 – 16

RESULTS

Phase 1

Through six individual interviews in Phase 1, parents responded to specific questions to target remaining areas of uncertainty of the applicability for the population. Specifically, they were probed with comprehension, paraphrasing, specific, and general questions (See Appendix B for full cognitive interview). One of the specific questions focused on the categorized time frame of the item measures (“*In your opinion, does the change in time reference in 1-8 from 9-16 make sense?*”). Table 5 below includes exemplar quotes highlighting consistent patterns of parents indicating need/desire for *greater distinction between experiences in childhood and adulthood*. In addition, a general probe about aspects that could improve the measure based on parents’ experiences (“*What changes would you suggest to make the measure better overall?*”) elicited another pattern of responses focusing on the inaccuracies of these items posed as being objective stressors, and the *need to include appraisal of the experience as a stressor* (Table 6). Qualitative data below is not comprehensive, as the focus of this portion of the study was clarity of the measure as well as improvements needed.

Table 5*Common Theme in Cognitive Interview Responses to Specific Probe: Timeframe*

Theme	Exemplars
<i>Distinction between experiences in childhood and adulthood</i>	<p>“1-8 could have been broken down a little more... maybe a section for childhood, teen years, to young adult years.”</p> <p>“Easy to answer... but the thoughts I’ve had when he was in childhood vs. college are very different.”</p> <p>“18 to present time makes sense, but for #1-8... these things have changed to much from high school to now... college to now. For example, #5 can be seen quite differently in childhood vs adulthood... You might get more valuable information if you split it up to just childhood and just adulthood.”</p> <p>“Maybe break up the timeframe... for example, for #6, I would say ‘yes’ until grade school, but ‘no’ once in middle school. Maybe ask how is your stress different now than it was in childhood?”</p> <p>“Hard sometimes when it’s overall over time because maybe it happened at age 5 but really isn’t an experience anymore.”</p>

Table 6*Common Theme in Cognitive Interview Responses to General Probe: Stressor Vs. Experience*

Theme	Exemplars
<i>Need to include appraisal of the experience as a stressor</i>	<p>“Measure level of stress... if these are things everyone goes through it doesn’t speak to how it adds to stress level, especially given SES and privilege. Do you find this disruptive to your personal happiness? Does it keep you up at night?”</p> <p>“If you want to get at what is stressful and how parents perceive that stress, use an open-ended question. You might get more nuanced answers and ‘yes’ and ‘no’ is hard to get nuance out of that.”</p> <p>“In answering these questions I wasn’t thinking about ‘stress’ except for a couple.”</p> <p>“A couple were a little unclear how to answer (like #6) because there are different stages of relief. The word ‘caregiving’ changes over time. It’s more stress now... will he lose his job, is he working efficiently? Creates more stress than before because it ties into #3 (future planning).”</p>

Lastly, Table 7 below outlines other themes that emerged following a general probe about aspects that could improve the measure based on parents' experiences (“*What changes would you suggest to make the measure better overall?*”). Specifically, parents shared stressors they have experienced that they felt were missing from the measure. However, one stressor presented (#1 listed below) was determined to fall under an existing item (#11; balancing autonomy and involvement/support), and another stressor presented (#2 listed below) was determined to fall under two potential existing items (#11; balancing autonomy and involvement/support, or #13; availability of appropriate adult ASD services). The other two stressors presented (#3 and #4 listed below), although interesting, were individual experiences and data-derived codes did not map onto qualitative patterns in thematic analysis. Thus, these items were not included in the adapted measure for the national survey.

Table 7

Cognitive Interview Responses to General Probe: Specific Items to Add

Theme	Exemplars
<i>Autonomy & involvement/support</i>	1. “One thing it doesn’t capture is huge amount of stress from navigating boundaries of being a therapist vs. parent. Still feel like I’m doing way more than I would like to be doing at this time in my life. But without that support from me I don’t know if he’d be successful.”
<i>Autonomy & involvement/support</i> <i>OR</i> <i>Appropriate adult ASD services</i>	2. “No one would provide the services I provide that would help him be successful... like access to his email to make sure he doesn’t miss any and make sure he’s responding appropriately.”
<i>Balance celebrating uniqueness & practicalities</i>	3. “Finding the balance between celebrating who they are vs. trying to make them fit into this world. Valuing how he thinks and lives, but practicalities of how he lives in the world are a different thing (job interviews, staying organized). Hard to strike that balance.”
<i>Employment disability disclosure</i>	4. “It lacks substantially with questions about employment, like job interview process, disclosure of their disability... No one was prepared for problems that arose with that. Regardless of your disability people have their biases.”

Given consistency in themes around differentiating the timeframe and subjective endorsement of items as stressors, the measure was adapted and IRB-approved before moving forward with the web-based survey (Appendix D). Specifically, questions 1-8 (dichotomous options for experiences since childhood to present time) was adapted to include response options by timeframe in which parents did have an experience listed (childhood only, adulthood only, both childhood and adulthood, neither). Additional items were added to measure stress appraisal, also with new timeframe response options as noted above. Dichotomous response options for questions 9-16 (experiences since age 18 to present time) remained, but additional items were added to measure stress appraisal if the item was endorsed.

Phase 2

Results for phase 2 of the study consist of bivariate correlations (Table 8), with supplemental qualitative data (Tables 9 - 12). Bivariate correlations were used to examine the relationships between variables measured. Additional correlational analyses examined relationships between parent stressors experienced (as indicated by counts computed from Accumulated Stressors Scale) and primary study variables from the originally proposed model. Significant associations included the positive relationship between caregiver burden and amount of stressors experienced across the lifespan, $r = .629, p \leq 0.001$, as well as a positive relationship between income adequacy (where higher numbers indicate less adequacy) and amount of stressors experienced across the lifespan, $r = .488, p = 0.008$.

Table 8*Correlations of the Assessed Variables*

	1	2	3	4	5	6	7	8	9	10	11
1. Social Support											
2. FTP Open	.471*										
3. FTP Limited	-.415*	-.083									
4. FTP Ambiguous	-.220	-.511**	.284								
5. Burden	-.288	-.430*	.316	.537**							
6. Satisfaction	-.014	-.063	-.348	-.057	-.493**						
7. Approach Cope	.185	.397*	.120	.137	.189	-.075					
8. Avoid Cope	-.135	-.044	.117	.318	.370	.148	.382*				
9. MIL Presence	.470*	.370	-.291	-.205	-.252	.182	.415*	-.111			
10. MIL Search	-.482**	-.396*	.074	.411*	.084	.395*	-.068	.397*	-.393*		
11. MCS	-.005	.042	.163	-.111	-.122	-.171	-.307	-.715**	.014	-.271	
12. PCS	.252	.173	.062	-.299	-.417*	.177	-.149	-.325	-.024	-.180	.127

Note. FTP = Future Time Perspective, MIL = Meaning in Life, MCS = Mental Component Summary, PCS = Physical Component Summary

** $p < 0.05$; ** $p \leq 0.01$*

Qualitative Findings: Stressors

Following completion of the Accumulated stressors scale, parents were provided with two open-ended questions regarding stressors that were not included in the measure, and regarding shifts in stress from childhood to adulthood. Following the data reduction process (RADaR) I went through four phases engaging in open coding, later followed by focused coding.

With emerging patterns at each phase, codes were categorized, and finally, converted into themes. Table 9-10 outline the resulting themes and subthemes from this coding process.

Of note, Braun and Clarke (2013) typically suggest to not use number counts in thematic analysis, as the use of numbers in qualitative research is in contrast with the constructivist approach used in most qualitative research.

Table 9

Themes and Subthemes: Parent Stressors Missing from Accumulated Stressors Scale

Question: What are other stressors parents of adults with ASD experience that were not included in the accumulated stressors measure?

Themes	Subthemes
Others' Lack of Understanding	Family Society Service providers
Child's Future Quality of Life	Relationships Independence
Providing Help	Finding a balance Adapting from a distance
Employment	Positive traits vs. social deficits Disability disclosure
Adapting to Unexpected Changes	Mental health

Others' Lack of Understanding

Questioning parents regarding stressors they have experienced that weren't captured by the measure led to one theme highlighting the stress and frustration experienced due to *others' lack of understanding* regarding the nuances of their child's ASD diagnosis and functional impairments, particularly HFA. This theme encapsulates the stress parents experience as a result

of misperceptions or judgements from others. Parents indicated experiencing this from their own *family members* (subtheme):

“Family members questioned us about decisions we made regarding his independence and support.”

Parents also expressed experiencing this from *society* (subtheme):

“Because my child is college capable academically with disability supports, so many people do not understand the stressors. That, in and of itself, is an additional stressor.”

“My child does not drive which has caused significant stress because the expectations and infrastructure in rural areas come with an expectation that adults drive.”

Lastly, parents have experienced this lack of understanding from *service providers* (subtheme):

“Expectations from service providers that my young adult should be managing communications/paperwork, etc.”

Child’s Future Quality of Life

Parents indicated a need for questions about their stress related to their desire for their child to have a successful and healthy life, but uncertainty in their child’s ability to reach this *quality of life*. Two subthemes emerged, highlighting concerns about their future life specifically related to developing meaningful *relationships* and their ability to obtain and overall level of *independence*:

“I worry about him making true friends and finding a soulmate. I don't want him to be lonely.”

“In general, his overall ability to be successful, live on his own, support himself, find a spouse, support a family. These are all things that are stressors to me.”

Providing Help

Many parents expressed the lack of questions surrounding a primary stressor of *providing help* (support, guidance, skills, limits) to their child with ASD, particularly stress with how to

find a balance (subtheme) in providing help in a manner that is beneficial to their child considering nuanced functional abilities. Some parents described complex stressors in finding this balance of providing help while highlighting the emotionality and relationship rifts that can accompany this:

“Feeling guilt over his lack of friendships and peer support. He is my son and I push him because I want him to be successful and contribute to society but inside I feel the pain of what he goes thru.”

“There is substantial stress caring for a child with ASD often due to the distorted perceptions of the child; where the child is battling their need for independence and their lack of abilities. This leads to a distorted view of the parent as someone as a barrier. The parent becomes the object of blame. It is very challenging to help an individual who does not want help, yet needs the help. Many individuals with ASD have mental health and emotional issues as a result of the lack of access to the life they feel they should have, yet struggle with.”

Others described a constant learning process finding the proper balance of when to provide help:

“Trying to navigate how much or how little parental intervention/help is appropriate has been an ongoing stressor throughout his childhood & into adulthood (i.e. how much should we help/rescue him vs should we let him "fail" at certain things?).”

In considering the theme of providing help, another subtheme emerged regarding a specific new stressor for parents after their child transitions to college or post-secondary education. There is stress surrounding the need to learn to adapt in how to provide help *from a distance*:

“Helping him find balance in work and personal care - he strives very hard to do well in school, has focus issues, and needs time management and stress reduction assistance. This is much harder now that he is 4 hours away at college.”

Employment

A theme of *employment* emerged as a stressor parents felt wasn't captured in the current measure. Parents expressed concerns related to their child's ability to obtain employment, specifically related to *social skills/behaviors despite their strengths/abilities* (subtheme) as a hard-working individual. Another subtheme emerged regarding parent concerns for their child to

disclose their disability, as they are uncertain of the potential negative effects to obtaining employment. One parent’s account clearly highlights both areas of stress within this realm of employment stress:

“Concerned that due to social challenges he may have difficulty in interview situations. Our son is intelligent, kind, and a superb employee. Knowing whether he should disclose that he has ASD is always a difficult decision because we don’t know how it will impact his chances of being hired.”

Adapting to Unexpected Changes

Lastly, some parents identified stressors surrounding the general need to *adapt to unexpected changes* in their child’s *mental health* (subtheme) and presentation over time, either due to a new setting/environment or not, for instance:

“New problems with depression and anxiety did not surface until he moved away from home.”

“Learning to understand his emerging personality, anxiety triggers and mood changes and navigating those things has been a lifelong stressor.”

Table 10

Themes and Subthemes: Difference in Parent Stress in Adulthood vs. Childhood

Question: How is parent stress different now than it was in childhood?

Themes	Subthemes
Concern for Child’s Future	Employment & Independence Meaningful relationships
Lack Support	Understanding from other parents Post-college
Providing Help	Lack of control Lack of reciprocity
Fear of Harm	Police Others
Less Stress	College transition/support program

Concern for Child's Future

Questioning parents regarding how their stress is different now (in adulthood) compared to previously (during their child's childhood) highlighted a primary theme of greater attention to and *concerns for their child's future*, across multiple domains that are considered to encapsulate a healthy and successful life, one of which is *employment and independence* (subtheme):

“Stress around if he will be able to live independently and hold a good job.”

“I worry a lot more about his future employment now.”

“I am now able to leave my adult son alone so I don't have to be with him all of the time. When he was young, he constantly had to have eyes on him. Now the concerns are more about whether he will be able to be independent and how to help him become so.”

One parent highlighted concerns of long-term independence (or lack thereof), with less focus on employment as parents noted above, but described the particularly heavy emotional turmoil when faced with the reality of her child's long-term dependency and future outcomes:

“Currently, while some milestones have been met, I believe there is simply an expectation that the routine established will continue during the remainder of my child's lifetime. It's scary to consider my child's future might depend completely upon my or some other entity's pushing my child in a direction. My child struggles horribly making logical, rational decisions and maintaining forward momentum and personal motivation beyond the boundary of the bedroom. Very worried we've gone as far as we are able ... although functionality appears reasonable when my child is submerged within various engagements. We have gone from raising the child to worrying the child cannot function when left to their "independence" ... never too concerned about the formative years. Now - very worried that my child might pass away in a dark room, alone and unnoticed. Horrifying.”

Another subtheme emerged regarding parent stress about their child's ability to obtain (and maintain) *meaningful relationships* both now and in the future, another important life domain that is particularly nuanced in the HFA population:

“I am less concerned my son will be able to live independently and thrive - he is extremely high functioning. I worry he won't develop true and meaningful relationships like he desires, as he is "awkward" and therefore people naturally avoid.”

“Our main concern now is that our son will be able to have a fulfilling social life. He's high functioning, so after graduation he will be living on his own at some point. Finding and keeping friends is something that concerns us a little.”

“Social inclusion for him has become much harder. He grew up in a small community where he was included and had many friends- everyone was kind. Now that he is in college he is having a really hard time connecting to people and that is heart breaking and terribly stressful for me.”

Lack Support

A theme of parents having a lack of support is a stressor in adulthood, which includes lack of support and understanding from other parents with adult children without ASD. One parent highlights how this lack of support from other parents is a continuance of this type of stressor since childhood, leading to further removal/separation from other parents:

“People no longer tell me that I'm "crazy" thinking my child could read when he "can't even talk" and just "accept that he has a disability and will never be in a typical school." Now, people are saying "What's the big deal? He's in college." I can't talk to the other parents whose kids are in college because our experiences are so different.

Other parents note this being a new stressor they haven't encountered to the full extent yet, but are aware of this lack of support after their child has completed college (subtheme):

“There is nothing to fall back on. We are pretty much on our own. No family support, no school support once the adult child exits the Transition program.”

Providing Help

Some parents highlighted the differences and added stress caused by trying to provide help to their child in adulthood while they are away at college, and the specific ways in which their child's transition into adulthood provides parents with novel experiences where they lack control (subtheme):

“It’s greater now because he is an adult and makes his own choices whereas before as parents we had control over what he could and couldn’t do. That control gave us security to lead him in more positive directions.”

“Distance makes it harder to really know daily what he is struggling with and being able to help him. We have great communication, but I can't just go see him at a moment's notice when he REALLY needs it. It is tougher teaching him coping skills from a distance.”

An additional subtheme emerged, focusing on parent’s accumulated stress with the lack of reciprocity or appreciation they have experienced over time while consistently trying to provide their child the help that is needed. This subtheme highlights cumulative effects of providing help to a child who does not want or appreciate parent sacrifices made:

“As our son has grown, he has become more and more angry and depressed with the battle to be independent, and the knowledge that he requires the support of others. The natural need for independence and need for romantic companionship do not disappear with a diagnosis of ASD. We battle every day with how to navigate living with an adult who does not appreciate our help and support, yet is unable to live independently. It is a challenge to continue to be an advocate for an individual who does not appreciate the time and energy involved in advocacy and care, after a lifetime of strong dedication, love, support, advocacy, medical & therapeutic interventions, loss of earned income from leaving my job, and marriage stress.”

Fear of Harm

Parents described a stressor of more recent onset, regarding their *fear of potential harm* of their child with ASD. The quotes below highlight one parents fear in particular related to *police*, which is likely reflective of the sociopolitical climate and current events:

“I now have to fear how legal authorities/police mishandle and misunderstand young adult males with ASD and act before investigating.”

Another parent shared this concern in relation to other individuals in society, particularly now that their child is distanced in another environment:

“My stress during childhood was about making sure he had all the resources and accommodations he needed. My stress now that he is away at college is that he will be taken advantage of, hurt, make poor decisions, etc.”

Less Stress

Lastly, some parents reported experiencing less stress during their child’s adulthood compared to childhood, specifically related to their experiences with services and support received through their respective college transition/support programs:

“He is understanding his diagnosis more and can live on his own. [His support program] is a huge stress relief.”

“My college aged daughter has support of a special program at her college. They have made a tremendous difference in her life, as well as ours. [The support program] at [her university] is fantastic!”

Qualitative Findings: COVID-19

At the end of the survey, parents were provided with two open-ended questions regarding how COVID-19 has affected parents generally, and what unique challenges or concerns COVID-19 has created for their children. Following the data reduction process (RADaR), I went through four phases engaging in open coding, later followed by focused coding. With emerging patterns at each phase, codes were categorized, and finally, converted into themes. Tables 11-12 outline the resulting themes and subthemes from this coding process.

Table 11

Themes and Subthemes: Effect of COVID-19 on Parents

Question: How has COVID-19 affected parents?

Themes	Subthemes
Losses	Death of loved ones Healthy habits & activities Freedoms
Emotional Toll	Stress/Anxiety Isolation Divisiveness & Conflicts
Occupational Toll	Hospital Teacher

Losses

When questioning parents regarding how the COVID-19 pandemic has affected them personally, four themes emerged, with a primary one being losses they have experienced, with a few parents noting experiencing the deaths of family members (sister, father-in-law, extended family) as an area of loss. Other parents noted being “less active” and decreased healthy habits, such as this parent:

“With less time at the office, I have gotten less exercise and eat less nutritiously at lunch.”

Another parent expressed stress surrounding their feelings of losing freedoms:

“Created a sense of anxiety due to freedoms disappearing--freedom of speech, freedom of assembly, freedom of religion, freedom to not wear a masks that don't work, freedom to have a job without consenting to an experimental vaccine.”

Emotional Toll

Understandably, parents expressed similar experiences of the pandemic overall taking an emotional toll on them, with multiple parents simply stating “general anxiety,” and “feeling isolated,” and other parents highlighting the emotional toll related to divisiveness and negative interpersonal interactions related to the pandemic specifically:

“The divisiveness & ‘ugliness’ in the news, on social media & in the public has taken a toll on me.

“A coworker purposely coughed in my face.”

Occupational Toll

Some parents shared having a particularly difficult experience during the pandemic due to their job, which created additional stress for these parents who work in hospitals and in schools:

“I work in a hospital and it’s been very exhausting and emotionally draining.”

“I teach, and it has been absolute chaos, followed by heroic adaptation, followed by realizing that society doesn't value any of what we have done or still do for children. Often we are treated like we are the cause of all the problems, and students have returned with great deficits in behavior and learning. It is a dumpster fire. I don't have adequate time for myself or my own children's needs because I'm supposed to fix everyone else's problems without support.”

Table 12

Themes and Subthemes: Effect of COVID-19 on Adults with Autism

Question: What are unique challenges or concerns for your child due to COVID-19?	
Themes	Subthemes
Increased Social Deficits	Loss of social opportunities Forming habits
Emotional Toll	Anxiety Rigidity
Health	Vaccine beliefs

Increased Social Deficits

When questioning parents regarding how the COVID-19 pandemic has affected their child with ASD, parents expressed new challenges and concerns for their child as a result of the pandemic effects. Four themes emerged, with a primary one being their child’s increased social deficits, largely related to the limits of social experiences:

“My ASD son went away to college the fall of 2020. He already struggled with making connections with people, and COVID has made that even harder for him.”

“He has not had enough social opportunities due to COVID.”

Within this realm, some parents expressed how the pandemic and social restrictions have led to behavior that has reinforced existing social isolation and led to concern for this behavior being further reinforced as a habit:

“My son has become even more reclusive. This has been a battle to get him back out and involved in the world.”

“Concern that my ASD child will form a new "habit" of staying away from others and shutting himself away in the name of social distancing.”

Emotional Toll

The emotional toll the pandemic has taken on these adults with ASD include increased anxiety and general emotional deterioration related to the social losses noted above. For example, some parents noted:

“My son's anxiety levels were much higher than before. He was very worried every time someone coughed. He was also worried about losing anyone close to him.”

“Covid quarantines and remote learning made my child feel extremely isolated.”

A subtheme of the emotional toll highlights the exacerbation of difficulties already experienced by some with ASD, specifically, rigidity in thinking:

“He is very rules oriented and it has always been a challenge to teach him moderation. He has a strong sense of responsibility and COVID has been a real stressor to him. Finding ways to encourage him and talk him down off the ledge has been a challenge sometimes.”

“He has had big emotions about people not following the rules.”

“Just worried because she is so black and white that others will make fun others or she will say the wrong thing to the wrong person and get hurt.”

Health

Lastly, parents encountered some difficult challenges related to their children’s health as it relates to their beliefs regarding bodily autonomy, specifically the COVID-19 vaccine:

“After receiving the first two doses, he refused to get the booster. He's worried about what might be in it that could cause long-term harm.”

“He is against vaccines so when he got covid had to be hospitalized for IV fluids.”

DISCUSSION

The current study provides areas of new insight and developments regarding novel measure development, and illumination of how the circumstances, needs, and stressors of parents of adults with ASD change with age.

Phase 1: Cognitive Interviews

In considering Phase 1 of the study, parents of adults with ASD who have completed college provided personal expertise to facilitate adaptations to the Accumulated Stressors scale. Consistent feedback highlighted: 1) the need to delineate a specific timeframe for parents to endorse experiences, as the experience in parenting a child with ASD is extremely variable and there are different weights placed on certain experiences at certain times, and 2) the need to ask about experiences as a stressor, as parents noted that despite the literature, some of the experiences to endorse were not a stressor for them. Adaptations to the measure per feedback from cognitive interviews with six parents was fruitful, as in Phase 2, completion of the measure with 28 parents demonstrated similar patterns.

During cognitive interviews parents were asked about specific experiences/stressors they have had that were not included in the measure that they considered necessary to include for this population of parents (see table 6). One stressor was considered to be covered in measurement item #11 (Balancing their autonomy and my involvement/support), and another stressor was considered to be covered by either measurement item #11 (Balancing their autonomy and my involvement/support), or measurement item #13 (Appropriate ASD adult services and/or interventions are available), and thus were not added to the measure prior to survey

dissemination. However, qualitative findings from open-ended survey questions in Phase 2 highlighted that other parents similarly felt this concept was not captured (see table 8; Providing help/Finding a balance).

Selective coding also highlighted two other stressors that were noted as items to include based on cognitive interviews (see table 6), but were not incorporated into the measure prior to survey dissemination as these stressors were based on one parent report, which respectively, did not map onto other themes. Based on qualitative findings from the Phase 2 survey, similar themes arose surrounding suggestions for inclusion of an item focused on nuanced concerns with employment (disability disclosure, maintenance of stable job, related social aspects). The final suggestion of an item from a parent during cognitive interviews regarding balance of celebrating child's uniqueness while being practical in life expectations was not similarly indicated throughout qualitative coding from survey responses, and thus may be that other parents who have similar experiences conceptualized this under measurement item #11 again (Balancing their autonomy and my involvement/support), or a stressor encapsulated by this different potential theme was simply not obtained in open-ended survey questions given the sample size. Notably, best practices in developing and validating a scale should range from about 5-15 cognitive interviews in two to three "rounds," which may be until saturation or when there are minimal new insights (Beatty & Willis, 2007; Willis, 2005). Although this process was not completed in the current study (as was not the originally proposed focus), the two primary qualitative themes that emerged regarding proposed timeframe and appraisal of stressors proved to be important and common experiences, given the response patterns in Phase 2 with 28 parents. Findings from both Phase 1 and Phase 2 in conjunction provide implications for future measure development, and the necessity of such a measure.

Phase 2: Survey Responses Focused on Accumulated Stressors and Bivariate Correlations

Overall, in analyzing themes that emerged from qualitative survey responses regarding parent stressors, many of the items could be considered to fall into existing categories/items present in the measure. Notably, similar themes emerged in response to two separate questions regarding parent stressors (what parents felt was missing from the Accumulated Stressors scale and how parents stress is different now in adulthood versus in childhood). Parents expressed how their current stress in adulthood is more focused on concern for their child's future (theme) and indicated that concern for their child's future quality of life (theme) was not accurately captured in the measure as it currently stands. However, these indicated themes could be considered to fall into existing categories/items already present in the measure. For example, the themes of stressors surrounding child's future quality of life (specifically considering employment and independence) could be captured by two existing items: 1) Considered who will provide care when you are no longer able to, and 2) Considered your child's future in terms of residence, employment, and general lifestyle. Thus, there are aspects that were not captured by the two items, which perhaps could be the vague/broad domain coverage in the items.

Another similar theme emerged across the two qualitative questions regarding missing items from the Accumulated Stressors measure and differences in stress during adulthood versus childhood, with a focus on others' lack of understanding of their child with ASD and parents' unique stressors, and parents indicating a lack of support from others as a result. This was not a theme that emerged during measure development or cognitive interviews, but was revealed from the 28 survey responses. Item #7 was presumed to measure this in the measure (Social isolation, or exclusion, or loss of social supports), but the themes that emerged from qualitative responses seem to provide a more unique aspect than just perception or loss of social support, as these

qualitative responses highlight interactions that may tap more into judgment, stigma, or expectations, that are important and specific types of stressors this population of parents face.

A third and final overlapping theme emerged across the two qualitative questions focused on parent stressors: providing help, which consistently encompassed stress regarding finding a balance to provide help, particularly in adulthood where there is distance between the parent and child, as well as an altered (lessened) level of control for parents, which are new experiences for the dyad overall. Within this realm, some parents expressed substantial, and quite different emotions as it relates to the “push-pull” relationship of providing help where they feel it’s needed. For example, one parent noted feelings of guilt because of their child’s lack of friendships, and although they push their child in this area in order to help them with social functioning and relationships in the long-term, they also describe internalizing the pain their child experiences as a result from their push to help. On the other hand, another parent expressed substantial frustration, emotional burnout, and consistent conflict as it relates to providing necessary help and advocacy that is not appreciated by the child, and in fact, the parent is further blamed regarding the child’s problems and lack of independence. These three overlapping themes and subthemes across the two qualitative questions focused on parent stressors highlight areas of improvement and further refinement of the Accumulated Stressors Scale. Inclusion of open-ended questions on the measure provided rich data unattainable through quantitative methods. Although the small sample size limits abilities to make claims or analyze the data from a mixed methods standpoint, there is substantial data indicating the need for a measure of stress specifically for parents of adult with ASD.

Although implications cannot be drawn from significant bivariate correlations due to sample size, interesting patterns of correlations should nonetheless be addressed. Specifically,

perceptions of social support were positively related to presence of meaning in life and open future time perspective, yet negatively related to search for meaning in life and limited future time perspective. Perceived social support is imperative for caregiver well-being (Cohen, 2004), and the quality and type of support for parents of adults with ASD is particularly important (Marsack & Samuel, 2017; Smith et al., 2012). The current findings demonstrate potential implications for the impacts social supports may have on parents' sense of (versus search for) meaning in life. Interestingly, relations among the multidimensional variable of future time perspective appear to follow a pattern opposite to what was expected when considering theoretical underpinnings of SST. Specifically, in addition to associations noted above, an open future time perspective related positively to approach coping and negatively to burden and search for meaning in life. Following SST, it was presumed that an open future time perspective would likely show fewer positive or minimal positive relationships with healthy factors (satisfaction, approach coping, presence of meaning in life), and greater relationship with poorer health factors (burden, avoidant coping, search for meaning in life). Alternatively, an ambiguous future time perspective was positively associated with burden and search for meaning in life. This is to be expected when conceptualizing ambiguity as uncertainty of future time remaining, particularly considering parents of adults with HFA. There are heightened uncertainties and worries related to their child's future when they are no longer able to provide care (Dudley et al., 2019), and many parents have not made long-term care plans (Van Bourgondien et al., 2014). Other qualitative research has shown ways in which some parents "lived one day at a time" to avoid thinking about the future while also taking a position of passive acceptance and hopelessness about future care services (Pryce et al., 2017). Thus, an ambiguous future time perspective may

relate to increased stress and “unfinished business” (Smith et al., 1995) that accompanies the looming need to engage in future planning for a loved one with a developmental disability.

Considering coping strategies, an approach coping perspective was positively related to presence of meaning in life and avoidant coping. The latter relation may reflect the fact that some parents are generally more active in engaging in a wide range of coping methods overall, including both approach and avoidant strategies. Avoidant coping was positively related to search for meaning in life, and strongly negatively related to overall mental health. These associations reflect similar patterns with research showing use of disengagement and distraction related to increased maladjustment overtime, and use of cognitive reframing related to better outcomes for mothers of children with ASD (Benson, 2014). Lastly, as expected, caregiver burden showed a negative relation with both caregiver satisfaction and physical health, whereas caregiver satisfaction showed a small but significant relation to search for meaning in life.

Implications and Future Directions

Findings from the current study may be applied to developing and validating an adapted Accumulated Stressors measure in the future, specifically with the adaptation of domains beyond the four from the originally proposed measure (future planning, self-care/social support, transition into young adulthood, services/unmet needs). For example, “future planning” may be considered to be adapted into a broader domain (e.g., “the future”) while adding more *specific* questions of stressors within this area based on parent responses from the current study (i.e., child’s future meaningful relationships, level of independence, employment, isolation, etc.). As noted above, the items as they exist on the current measure may be overly vague, such that parents provided qualitative accounts of stressors they felt weren’t captured in the items as they existed. Further delineating overarching domains with more specified items as they relate to

subthemes that were revealed would be a beneficial adaptation and future direction for measure development. Additionally, findings indicate that appraisal of the experiences as stressors or not was important, and may suggest a future adaptation to measure level of stress appraisal.

Although there are clear themes that have emerged regarding parent stress, there are nuances of experiences (and other factors such as SES, resources, etc.) amongst these parents. Appraisal of an experience as a stressor without severity of stress felt won't capture the heterogeneity in this population of parents.

This is further demonstrated by the fact that overlapping themes emerged in areas of future employment, level of independence, development of meaningful relationships, lack of understanding from others, and providing help to their child with ASD, while at the same time the qualitative findings emphasize the heterogeneity of experiences and stressors in this population, which may be a result of ASD severity (even within a HFA population), resources, and cultural factors. In order to develop a valid measure it would likely be necessary to complete cognitive interviews in focus groups, going through multiple rounds with parent participants from college transition and support programs. Pooling from a variety of colleges and programs (e.g., community colleges, universities) with a variety of relevant factors (e.g., cost of program, geographic region/area) would provide the necessary level of heterogeneity for the measure development process. For example, one parent indicated a newfound fear of harm for her child at the hands of police and their potential mishandling or misunderstanding the presentation of a male adult with ASD, likely brought on by 1) increased coverage of police excessive use of force and 2) specifically, the murder of Elijah McClain by police. There are important cultural aspects necessary to address (race, SES, rural vs. urban residence) to ensure generalizability across such a heterogeneous sample. Overall, a valid measure of parent accumulated stressors would then be

beneficial to use in these college transition and support programs to get a better understanding of the needs of parents overtime, and where or how to allocate respective assistance or resources.

Again, the inclusion of open-ended questions provided meaningful data, but it is unfortunate that data collection did not yield a large enough sample size, as many of the themes parents highlight may seem relevant to quantitative measures (perceived social support, burden, future time perspective). Inclusion of such themes may have allowed a more integrated analysis and ability to supplement proposed relationships in the Double ABCX Model. Although implications are limited due to this, qualitative themes generally reveal the substantial and ongoing stressors parents face in adulthood and as they continue to age, and quantitative findings suggest important relationships between supports and internal mechanisms with other factors that may impact emotional/mental health outcomes for parents of adults with HFA. For instance, perceptions of social support are positively related to a presence of meaning in life, and less of a search for meaning in life. Research shows relations between meaning in life, increased psychological and physical health, effective coping, and decreased stress (Hooker et al., 2018; Sherman & Simonton, 2012). Qualitative themes from the current study regarding a lack of support/understanding from others (and the additional stress this adds) highlights the need for specific social interventions (e.g., peer groups, peer support specialists) with fellow parents who have an adult child with ASD. For example, a peer support intervention for caregivers and adults with developmental disabilities that was focused on future planning significantly decreased caregiver burden and contributed to completion of specific future planning goals (Heller & Caldwell, 2006).

Additionally, caregiver burden was negatively related to overall physical well-being, and positively related to an ambiguous future time perspective. Although there is more research to be

done on ambiguity in future time perspective, it has been noted to have a negative relation with life satisfaction and optimism (Brothers et al., 2014). Targeting caregiver burden for these parents will necessitate a reduction in stressors experienced which some parents noted was achieved with the help of their child's college transition/support program. Thus, greater services provided to parents through these programs (including the addition of peer support interventions noted above), or referrals to mental health providers with knowledge and experience about ASD, problem-solving therapy or other forms of cognitive behavioral therapy may assist parents to reduce aspects of burden and focus on future goals/planning as it relates to their own life, along with future planning for their child with ASD. Overall, the current study provides a springboard for studies on measure development as well as studies assessing specific lifespan considerations for parents of adults with ASD. In the future, a mixed methods design would likely provide additional quality and content to the data, given the unique and nuanced aspects that resulted from the current qualitative data.

Limitations

The main limitations relate to participant recruitment and methodological integrity of the qualitative analysis. Unfortunately, cultural diversity is a common limitation in the research and literature surrounding ASD and parent/familial processes (Hall et al., 2017). The current study was no exception, as the study sample primarily consisted of parents who identified as White, well-educated, and financially well-off, thus, limiting the generalizability of findings. Given the specific population of focus (parents of adults with HFA during the transition into young adulthood) recruiting through college transition/support programs was considered to be the best way to reach a large number of these parents. However, some of these programs were contracted with the universities' office of disability services. It is possible that that subset of programs may

not have any involvement, or even ability, to contact students' parents. In addition, based on email responses from a few program directors, it is clear that there is a high demand for research participants with this specific population, given statements of being overwhelmed with outside research requests. It would be beneficial to all (directors, children, parents, researchers) to develop a consortium with collaborative projects and data sharing in order to reduce participant burden and enhance research efforts. This is an important consideration given future directions noted above regarding further measure development based on the current study. Following the cognitive interview process, survey administration with the appropriate sample size is necessary for proper scale development, with a common rule of thumb being a 10:1 ratio of respondents to items (Nunnally, 1978). Others (Guadagnoli & Velicer, 1988) have noted a minimum sample of 300 to 450 is necessary to psychometrically identify pattern comparability.

There may be limitations in recruitment related to the COVID-19 pandemic. As parents noted in qualitative responses, they are not alone in experiencing the ongoing effects of anxiety, isolation, stress, and increased areas of concern for their child with ASD also as a result of COVID-19. Parents are juggling greater demands caring for themselves and their children, and completing online surveys regarding stress and other aspects of their lives may not be a highly desirable experience. Although I cannot make proven claims about this, it is an important factor to note regarding recruitment difficulties. Notably, one program director reported that they shared the survey with approximately 70 parents, and survey responses revealed only 3 parents from this program participated. Another program director confirmed they shared the survey to parents of their program, and although it is unknown how many parents it was sent to, survey responses revealed that no parents from that program participated in the study. In order to obtain the needed sample size for proper data analysis it may be beneficial to include compensation or

chance of compensation (i.e., gift card) to increase participant engagement. Even though COVID-19 may have influenced participation, some individuals may be more interested or willing to participate despite those factors if there is a chance of monetary compensation. Additionally, collecting data over a number of years through college transition and support programs would also address data collection flaws in the current study. Data collection for Phase 2 was collected over the course of four months, which proved to be an inadequate length of time.

Lastly, there are issues of methodological rigor, including important aspects of fidelity to subject matter and utility in achieving research goals (Levitt et al., 2018). Given the shift in analytic plan from quantitative to qualitative analysis, data reduction processes were completed based on perspectives of a single researcher. Although completing coding through multiple phases of an iterative process was intended to increase perspective management, researcher bias in coding and analysis structure exists. Development of a stable perspective and work to limit the effect of a singular perspective on the data could be appropriately addressed by using multiple coders and developing interrater reliability and consensus on coding themes and subthemes through each phase of coding. In addition, although qualitative findings are grounded in evidence (using quotes, excerpts, or descriptions of researcher engagement in data collection; Levitt et al., 2018), thematic analysis using selective and data-derived coding facilitated a reduction of the data for specific expressions of disparate experiences or perceptions of measure items including content, formatting, or wording (Phase 1), and responses to four specific open-ended questions in Phase 2 regarding the Accumulated Stressors Scale and impacts of the COVID-19 pandemic. Although thematic analysis was deemed the best approach to maintain the fidelity and utility in achieving research goals in the circumstances, this reductive method (particularly RADaR) limits the potential richness of the data that may be implicative of other important caregiving aspects

that were not deemed to fit into the research question at hand. Supplemental checks could strengthen the current research findings by obtaining participant feedback on findings of themes and subthemes. Although there are multiple examples of checks added to qualitative analysis to better support claims per the Journal Article Reporting Standards (JARS) for qualitative research (Levitt et al., 2018), utilizing participant feedback for the findings would nicely integrate into future processes of more cognitive interviews and measure development initiatives.

REFERENCES

- Abbeduto, L., Seltzer, M. M., Shattuck, P., Krauss, M. W., Osmond, G., & Murphy, M. M. (2004). Psychological well-being and coping in mothers of youths with autism, Down syndrome, or fragile X syndrome. *American Journal on Mental Retardation*, *109*, 237–254.
- Abramson, T. A. (2015). Older adults: The “Panini sandwich” generation. *Clinical Gerontologist*, *38*, 251-267.
- Altieri, M. J., & von Kluge, S. (2009). Searching for acceptance: Challenges encountered while raising a child with autism. *Journal of Intellectual and Developmental Disability*, *34*, 142–152.
- American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington, DC: American Psychiatric Association, DSM-IV.
- American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Association, DSM-V.
- Bagenstos, S. R. (2015). *The disability cliff*. Democracy journal. <https://democracyjournal.org/magazine/35/the-disability-cliff/>
- Baltes, P., Lindenberger, U., & Staudinger, U. M. (2006). Lifespan theory in developmental psychology. In W. Damon (Series Ed.) & R. M. Lerner (Vol. Ed.), *Handbook of child psychology: Vol. 1. Theoretical models of human development* (6th ed., pp. 569– 644). Hoboken, NJ: Wiley.
- Barker E. T., Hartley S .L., Seltzer M. M., Greenberg, J. S., Floyd, F. J., & Orsmond, G. I. (2011). Trajectories of emotional well-being in mothers of adolescents and adults with autism. *Developmental Psychology* *47*, 551–561.
- Battista, J., & Almond, R. (1973). The development of meaning in life. *Psychiatry*, *36*, 409–427.
- Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research*, *51*, 702–714.
- Beatty, P.C., & Willis, G.B. (2007). Research synthesis: The practice of cognitive interviewing. *Public Opinion Quarterly*, *71*, 287–311.
- Benson, P. R. (2014). Coping and psychological adjustment among mothers of children with ASD: An accelerated longitudinal study. *Journal of Autism and Developmental Disorders*, *44*, 1793–1807.

- Bentler, P. M., & Chou, C. P. (1987). Practical issues in structural modeling. *Sociological Methods & Research, 16*, 78-117.
- Blacher, J., Kraemer, B. R., & Howell, E. J. (2010). Family expectations and transition experiences for young adults with severe disabilities: Does syndrome matter? *Advances in Mental Health and Learning Disabilities, 4*, 3–16.
- Blacher, J., & McIntyre, L. L. (2006). Syndrome specificity and behavioural disorders in young adults with intellectual disability: Cultural differences in family impact. *Journal of Intellectual Disability Research, 50*, 184–198.
- Boomsma, A. (1982). Robustness of LISREL against small sample sizes in factor analysis models. In K. G. Jöreskog & H. Wold (Eds.) *Systems under indirect observation: Causality, structure, prediction* (149–173). Amsterdam, Netherlands: Elsevier.
- Boomsma, A. (1985). Nonconvergence, improper solutions, and starting values in LISREL maximum likelihood estimation. *Psychometrika, 50*, 229-242.
- Bouma, R., & Schweitzer, R. (1990). The impact of chronic childhood illness on family stress: A comparison between autism and cystic fibrosis. *Journal of Clinical Psychology, 46*, 722–730.
- Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. Sage Publications Ltd: London
- Bristol, M. (1987). Mothers of children with autism or communication disorders: Successful adaptation and the double ABCX model. *Journal of Autism and Developmental Disorders, 17*, 469–486.
- Bromley, J., Hare, D. J., Davison, K., & Emerson, E. (2004). Mothers supporting children with autistic spectrum disorders: Social support, mental health status and satisfaction with services. *Autism, 8*, 409–423.
- Brothers, A., Chui, H., & Diehl, M. (2014). Measuring future time perspective across adulthood: Development and evaluation of a brief multidimensional questionnaire. *The Gerontologist, 54*, 1075–1088.
- Burke, M. & Heller, T. (2016). Individual, parent and social–environmental correlates of caregiving experiences among parents of adults with autism spectrum disorder. *Journal of Intellectual Disability Research, 60*, 401-411.
- Carstensen, L. L. (1995). Evidence for a life-span theory of socioemotional selectivity. *Current Directions in Psychological Science, 4*, 151–156.
- Carstensen, L. L. (2006). The influence of a sense of time on human development. *Science, 312*, 1913–1915.

- Carstensen, L. L., & Fredrickson, B. L. (1998). Influence of HIV status and age on cognitive representations of others. *Health Psychology, 17*, 494–503.
- Carstensen, L. L., Fung, H. H., & Charles, S. T. (2003). Socioemotional selectivity theory and the regulation of emotion in the second half of life. *Motivation and Emotion, 27*, 103–123.
- Carstensen, L. L., & Lang, F. R. (1996). Future Orientation Scale. Unpublished manuscript, Stanford University.
- Carstensen, L. L., & Mikels, J. A. (2005). At the intersection of emotion and cognition: Aging and the positivity effect. *Current Directions in Psychological Science, 14*, 117–121.
- Carver, C. S. (1997). You want to measure coping but your protocol's too long: Consider the Brief COPE. *International Journal of Behavioral Medicine, 4*, 92–100.
- Carver, C. S., Scheier, M. F., & Weintraub, J. K. (1989). Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology, 56*, 267–283.
- Centers for Disease Control and Prevention. (2020). Community Report on Autism: Autism and Developmental Disabilities Monitoring Network, United States 2020.
- Charles, S. T., & Carstensen, L. L. (2009). Social and emotional aging. *Annual Review of Psychology, 61*, 383–409.
- Charles, S. T., & Hong, J. (2016). Theories of emotional well-being and aging. In V.L. Bengtson, & R.A. Setterston (Eds.) *Handbook of theories of aging* (235-257). New York: Springer.
- Cohen, S. (2004). Social relationships and health. *American Psychologist, 59*, 676-684.
- College Programs*. (n.d.). College Autism Spectrum.
<https://collegeautismspectrum.com/collegeprograms/>
- Collins, D. (2007). Analysing and interpreting cognitive interview data: A qualitative approach. Proceedings of the 6th Questionnaire Evaluation Standard for Testing Conference, Ottawa, Statistics Canada.
- Crumbaugh, J. C., & Maholick, L. T. (1964). An experimental study in existentialism: The psychometric approach to Frankl's concept of noogenic neurosis. *Journal of Clinical Psychology, 20*, 200–207.
- Dabrowska, A., & Pisula, E. (2010). Parenting stress and coping styles in mothers and fathers of pre-school children with autism and Down syndrome. *Journal of Intellectual Disability Research, 54*, 266–280.

- Dudley, K. M., Klinger, M. R., Meyer, A., Powell, P., & Klinger, L. G. (2019). Understanding service usage and needs for adults with ASD: The importance of living situation. *Journal of Autism and Developmental Disorders, 49*, 556–568.
- Eaves, L. C., & Ho, H. H. (2008). Young adult outcome of autism spectrum disorders. *Journal of Autism and Developmental Disorders, 38*, 739–747.
- Edwards, T. L., Watkins, E. E., Lotfizadeh, A. D., & Poling, A. (2012). Intervention research to benefit people with autism: How old are the participants? *Research in Autism Spectrum Disorders, 6*, 96–99.
- Eisenberg, S. A., Shen, B. J., Schwarz, E. R., & Mallon, S. (2012). Avoidant coping moderates the association between anxiety and patient-rated physical functioning in heart failure patients. *Journal of Behavioral Medicine, 35*, 253-261.
- Eisenhower, A. S., Baker, B. L., & Blacher, J. (2005). Preschool children with intellectual disability: Syndrome specificity, behaviour problems, and maternal well-being. *Journal of Intellectual Disability Research, 49*, 657–671.
- English, T., & Carstensen, L. L. (2014). Selective narrowing of social networks across adulthood is associated with improved emotional experience in daily life. *International Journal of Behavioral Development, 38*, 195–202.
- Esbensen, A. J., Bishop, S. L., Seltzer, M. M., Greenberg, J. S., & Taylor, J. L. (2010). Comparisons between individuals with autism spectrum disorders and individuals with Down syndrome in adulthood. *American Journal on Intellectual and Developmental Disabilities, 115*, 277–290.
- Esbensen, A. J., Seltzer, M. M., Lam, K. S. L., & Bodfish, J. W. (2009). Age-related differences in restricted repetitive behaviors in autism spectrum disorders. *Journal of Autism and Developmental Disorders 39*, 57–66.
- Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou, X., & Abbott, R. (2009). Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. *Autism, 13*, 375–387.
- Fujiura, G. T., & Park, H. (2003). *The demography of aging caretakers: Implications of the greying of family households*. Chicago: University of Illinois at Chicago, Department of Disability and Human Development.
- Gerhardt, P. D., & Lanier, I. (2011). Addressing the needs of adolescent and adults with autism: A crisis on the horizon. *Journal of Contemporary Psychotherapy, 41*, 37–45.

- Giambattista, C., Ventura, P., Trerotoli, P., Margari, M., Palumbi, R., & Margari, L. (2019). Subtyping the autism spectrum disorder: Comparison of children with high functioning autism and asperger syndrome. *Journal of Autism and Developmental Disorders, 49*, 138–150.
- Greenberg, J.S., Seltzer, M.M., Krauss, M., Chou, R.J-A., & Hong, J. (2010). The effect of quality of the relationship between mothers and adult children with schizophrenia, autism, or down syndrome on maternal well-being: The mediating role of optimism. *American Journal of Orthopsychiatry, 74*, 14-25.
- Guadagnoli, E., & Velicer, W.F. (1988). Relation of sample size to the stability of component patterns. *Am Psychol Assoc., 103*, 265–275.
- Ha, J. H., Hong, J., Seltzer, M. M., & Greenberg, J. S. (2008). Age and gender differences in the well-being of midlife and aging parents with children with mental health or developmental problems: Report of a national study. *Journal of Health and Social Behavior, 49*, 301–316.
- Haber, M. G., Cohen, J. L., Lucas, T., & Baltes, B. B. (2007). The relationship between self-reported received and perceived social support: A meta-analytic review. *American Journal of Community Psychology, 39*, 133-144.
- Hall, H. R., Fruh, S., Zlomke, K., & Swingle, H. (2017). A qualitative analysis of the experiences of minority parents of children with Autism Spectrum Disorder. *Advances in Neurodevelopmental Disorders, 1*, 79–88.
- Hare, D. J., Pratt, C., Burton, M., Bromley, J., & Emerson, E. (2004). The health and social care needs of family carers supporting adults with autistic spectrum disorders. *Autism, 8*, 425–444.
- Hastings, R. P., Kovshoff, H., Brown, T., Ward, N. J., Espinosa, F. & Remington, B. (2005b). Coping strategies in mothers and fathers of preschool and school-age children with autism. *Autism 9*, 377–91.
- Hastings, R.P., & Taunt, H.M. (2002). Positive perceptions in families of children with developmental disabilities. *American Journal on Mental Retardation, 107*, 116-127.
- Hayes S. A. & Watson S. L. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders, 43*, 629–42.
- Heller, T., & Caldwell, J. (2006). Supporting aging caregivers and adults with developmental disabilities in future planning. *Mental Retardation, 44*, 189-202.
- Heller, T., Caldwell, J., & Factor, A. (2007). Aging family caregivers: Policies and practices. *Mental Retardation and Developmental Disabilities Research Reviews, 13*, 136–142.

- Hicks, J. A., Trent, J., Davis, W. E., & King, L. A. (2012). Positive affect, meaning in life, and future time perspective: An application of socioemotional selectivity theory. *Psychology and Aging, 27*, 181–189.
- Hill, R. (1949). *Families under stress*. New York: Harper.
- Hill, R. (1958). Social stresses on the family. *Social Casework, 39*, 139-150.
- Hines, M., Balandin, S., & Togher, L. (2014). The stories of older parents of adult sons and daughters with autism: A balancing act. *Journal of Applied Research in Intellectual Disabilities, 27*, 163–173.
- Hooker, S. A., Masters, K. S., & Park, C. L. (2018). A meaningful life is a healthy life: A conceptual model linking meaning and meaning salience to health. *Review of General Psychology, 22*, 11-24.
- Howlin, P. (2003). Outcome in high-functioning adults with autism with and without early language delays: Implications for the differentiation between autism and Asperger syndrome. *Journal of Autism and Developmental Disorders, 33*, 3-13.
- Howlin, P. (2004). *Autism and Asperger syndrome: Preparing for adulthood*. (2nd ed.). Routledge.
- Howlin, P. (2013). Outcomes in adults with autism spectrum disorders. In F.R. Volkmar, S.J. Rogers, R. Paul, & K.A. Pelphrey (Eds.) *Handbook of autism and pervasive developmental disorders* (97-116). Hoboken, NJ: Wiley.
- Ingersoll-Dayton, B., Morgan, D., & Antonucci, T. (1997). The effects of positive and negative social exchanges on aging adults. *Journal of Gerontology: Social Sciences, 52B*, 190–199.
- Johnson, N., Frenn, M., Feetham, S., & Simpson, P. (2011). Autism spectrum disorder: Parenting stress, family functioning and health-related quality of life. *Families, Systems, & Health, 29*, 232–252.
- Jorm, A. F., Windsor, T. D., Dear, K. B. G., Anstey, K. J., Christensen, H., & Rodgers, B. (2005). Age group differences in psychological distress: The role of psychosocial risk factors that vary with age. *Psychological Medicine, 35*, 1253–1263.
- Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child, 2*, 217–250.
- Kaplan, D. (2000). *Structural equation modeling: Foundations and extensions*. Newbury Park, CA: Sage.
- Kasten, L. (1993). Justification for 12-item Meaning in Caregiving questionnaire. Unpublished manuscript, New England Research Institutes.

- Kausar, S., Jevne, R. F., & Sobsey, D. (2003). Hope in families of children with developmental disabilities. *Journal on Developmental Disabilities, 10*, 35–46.
- Kellough, J. L., & Knight, B. G. (2012). Positivity effects in older adults' perception of facial emotion: The role of future time perspective. *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences, 67*, 150–158.
- Kline, R. B. (2015). *Principles and practice of structural equation modeling*. Guilford publications.
- Krauss, M. W. & Seltzer, M. M. (2000). An unanticipated life: The impact of lifelong caregiving. In H. Bersani (Ed.) *Responding to the challenge: International trends and current issues in developmental disabilities* (173-188). Brookline, MA: Brookline Books.
- Krauss, M. W., Seltzer, M. M., & Jacobson, H. T. (2005). Adults with autism living at home or in non-family settings: Positive and negative aspects of residential status. *Journal of Intellectual Disability Research, 49*, 111–124.
- Lavee, Y., McCubbin, H., & Patterson, J. (1985). The double ABCX model of family stress and adaptation: An empirical test by analysis of structural equations with latent variables. *Journal of Marriage and Family, 47*, 811-825.
- Lawton, M.P., Moss, M., Fulcomer, M., & Kleban, M.H. (1982). A research and service-oriented multilevel assessment instrument. *Journal of Gerontology 37*, 91–9.
- Lawton, M.P., Moss, M., Kleban, M.H., Glicksman, A., & Rovine, M. (1991). A two-factor model of caregiving appraisal and psychological well-being. *Journal of Gerontology, 46*, 181-189.
- Lawton, M.P., Moss, M., Hoffman, C., & Perkinson, M. (2000). Two transitions in daughters' caregiving careers. *The Gerontologist, 40*, 437-448.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer.
- Levitt, H.M., Bamberg, M., Creswell, J.W., Frost, D.M., Josselson, R., & Suarez-Orozco, C. (2018). Journal article reporting standards for qualitative primary, qualitative meta-analytic, and mixed methods research in psychology: The APA publications and communications board task force report. *American Psychologist, 73*, 26-46.
- Levy, A., & Perry, A. (2011). Outcomes in adolescents and adults with autism: A review of the literature. *Research in Autism Spectrum Disorders, 5*, 1271–1282.
- Lounds, J., Seltzer, M.M., Greenberg, J.S., & Shattuck, P.T. (2007). Transition and change in adolescents and young adults with autism: Longitudinal effects on maternal well-being. *American Journal on Mental Retardation, 112*, 401–417.

- Lu, M., Li, A. Y., Fung, H. H., Rothermund, K., & Lang, F. R. (2018). Different future time perspectives interplay in predicting life satisfaction. *GeroPsych, 31*, 103–113.
- Magana, S., & Smith, M. J. (2006). Health outcomes of midlife and older Latina and Black American mothers of children with developmental disabilities. *Mental Retardation, 44*, 224–234.
- Mandell, D. S., Wiggins, L. D., Carpenter, L. A., Daniels, J., DiGuseppi, C., Durkin, M. S., Giarelli, E., Morrier, M. J., Nicholas, J. S., Pinto-Martin, J. A., Shattuck, P. T., Thomas, K. C., Yeargin-Allsopp, M., & Kirby, R. S. (2009). Racial/ethnic disparities in the identification of children with autism spectrum disorders. *American Journal of Public Health, 99*, 493–498.
- Manning, M. M., Wainwright, L., & Bennett, J. (2011). The double ABCX model of adaptation in racially diverse families with a school-age child with autism. *Journal of Autism and Developmental Disorders, 41*, 320–331.
- Marsack, C. N., & Samuel, P. S. (2017). Mediating effects of social support on quality of life for parents of adults with autism. *Journal of Autism and Developmental Disorders, 47*, 2378–2389.
- Marsack, C. N., & Perry, T. E. (2018). Aging in place in every community: Social exclusion experiences of parents of adult children with autism spectrum disorder. *Research on Aging, 40*, 535–557.
- Maynard, J. (2015). Preparing for the ‘Autism Tsunami’: How will U.S. help autistic children transitioning to adulthood? Retrieved from <https://www.techtimes.com/articles/26106/20150112/preparing-for-the-autism-tsunami-how-will-u-s-help-autistic-children-transitioning-to-adulthood.htm>
- McCubbin, H. I., & Patterson, J. M. (1983). The family stress process: The double ABCX model of family adjustment and adaptation. *Marriage and Family Review, 6*, 7–37.
- McKnight, P.E., & Kashdan, T.B. (2009). Purpose in life as a system that creates and sustains health and well-being: An integrative, testable theory. *Review of General Psychology, 13*, 242–251.
- McStay, R. L., Trembath, D., & Dissanayake, C. (2014). Stress and family quality of life in parents of children with Autism Spectrum Disorder: Parent gender and the double ABCX model. *Journal of Autism and Developmental Disorders, 44*, 3101–3118.
- Miller, D. (1981). The 'sandwich' generation: Adult children of the aging. *Social Work, 26*(5), 419–423.
- Miltiades, H.B., & Pruchno, R. (2002). The effect of religious coping on caregiving appraisals of mothers of adults with developmental disabilities. *The Gerontologist, 42*, 82–91.

- Montes, G., & Halterman, J. S. (2007). Psychological functioning and coping among mothers of children with autism: A population-based study. *Pediatrics, 119*, 1040–1046.
- Morrell, M. F., & Palmer, A. (2006). *Parenting across the autism spectrum: Unexpected lessons we have learned*. Jessica Kingsley Publishers.
- Mullins, J. B. (1987). Authentic voices from parents of exceptional children. *Family Relations, 36*, 30–33.
- Muthén, L. K., & Muthén, B. O. (2002). How to use a Monte Carlo study to decide on sample size and determine power. *Structural Equation Modeling, 9*, 599–620.
- National Alliance for Caregiving (NAC) and AARP Public Policy Institute, Caregiving in the U.S., 2015 (Bethesda, MD: NAC, and Washington, DC: AARP, June 2015).
- Newman, L., Wagner, M., Cameto, R., & Knokey, A.M. (2009). The post-high school outcomes of youth with disabilities up to 4 years after high school. A report from the National Longitudinal Transition Study-2 (NLTS2) (NCSE 2009–3017). Menlo Park, CA: SRI International.
- Nunnally, J.C. (1978). *Psychometric Theory*. New York, NY: McGraw-Hill.
- Orsmond, G. I., Seltzer, M. M., Greenberg, J. S., & Krauss, M. W. (2006). Mother–child relationship quality among adolescents and adults with autism. *American Journal on Mental Retardation, 111*, 121–137.
- Pakenham, K. I. (1999). Adjustment to multiple sclerosis: Application of a stress and coping model. *Health Psychology, 18*, 383–392.
- Pakenham, K. I., Samios, C., & Sofronoff, K. (2005). Adjustment in mothers of children with Asperger syndrome: An application of the double ABCX model of family adjustment. *Autism, 9*, 191–212.
- Palmer, A. (2006). *Realizing the college dream with autism or Asperger syndrome: A parent's guide to student success*. Jessica Kingsley Publishers.
- Paynter, J., Riley, E., Beamish, W., Davies, M., & Milford, T. (2013). The double ABCX model of family adaptation in families of a child with an autism spectrum disorder attending an Australian early intervention service. *Research in Autism Spectrum Disorders, 7*, 1183–1195.
- Piazza, V. E., Floyd, F. J., Mailick, M. R., & Greenberg, J. S. (2014). Coping and psychological health of aging parents of adult children with developmental disabilities. *American Journal of Intellectual and Developmental Disabilities, 119*, 186–198.

- Pisula, E. (2007). A comparative study of stress profiles in mothers of children with autism and those of children with Down syndrome. *Journal of Applied Research in Intellectual Disabilities, 20*, 274–278.
- Pozo, P., & Sarriá, E. (2015). Still stressed but feeling better: Well-being in autism spectrum disorder families as children become adults. *Autism, 19*, 805–813.
- Pozo, P., Sarriá, E., & Brioso, A. (2014). Family quality of life and psychological well-being in parents of children with autism spectrum disorders: A double ABCX model. *Journal of Intellectual Disability Research, 58*, 442–458.
- Pruchno, R. A., & McMullen, W. F. (2004). Patterns of service utilization by adults with a developmental disability: Type of service makes a difference. *American Journal on Mental Retardation 109*, 362–378.
- Pryce, L., Tweed, A., Hilton, A., & Priest, H. M. (2017). Tolerating uncertainty: Perceptions of the future for ageing parent carers and their adult children with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 30*, 84–96.
- Rutter, M., Kim-Cohen, J., & Maughan, B. (2006). Continuities and discontinuities in psychopathology between childhood and adult life. *Journal of Child Psychology & Psychiatry, 47*, 276–295.
- Rutter, M., LeCouteur, A., & Lord, C. (2003). *Autism Diagnostic Interview – Revised*. Los Angeles: Western Psychological Services.
- Ryan, K., Gannon-Slater, N., & Culbertson, M.J. (2012). Improving survey methods with cognitive interviews in small- and medium-scale evaluations. *American Journal of Evaluation, 33*, 414–430.
- Ryff, C.D. (2014). Psychological well-being revisited: Advances in the science and practice of eudaimonia. *Psychotherapy and Psychosomatics, 83*, 10–28.
- Schopler, E. (1971). Parents of psychotic children as scapegoats. *Journal of Contemporary Psychotherapy, 4*, 17–22.
- Schreiber, J. B., Nora, A., Stage, F. K., Barlow, E. A., & King, J. (2006). Reporting structural equation modeling and confirmatory factor analysis results: A review. *The Journal of Educational Research, 99*, 323–338.
- Schwartz, C., & Gidron, R. (2002). Parents of mentally ill adult children living at home: Rewards of caregiving. *Health & Social Work, 27*, 145–154.
- Schulenberg, S.E., Strack, K.M., & Buchanan, E.M. (2011). The meaning in life questionnaire: Psychometric properties with individuals with serious mental illness in an inpatient setting. *Journal of Clinical Psychology, 67*, 1210–1219.

- Seltzer, M. M., Greenberg, J. S., Hong, J., Smith, L. E., Almeida, D. M., Coe, C., & Stawski, R. S. (2010). Maternal cortisol levels and behavior problems in adolescents and adults with ASD. *Journal of Autism and Developmental Disorders*, *40*, 457–469.
- Seltzer, M. M., Krauss, M. W., Orsmond, G. I., & Vestal, C. (2000). Families of adolescents and adults with autism: Uncharted territory. In L.M. Glidden (Ed.) *International review of research on mental retardation* (Vol. 23). San Diego: Academic Press.
- Shattuck, P. T., Narendorf, S. C., Cooper, B., Sterzing, P. R., Wagner, M., & Taylor, J. L. (2012). Postsecondary education and employment among youth with an autism spectrum disorder. *Pediatrics*, *129*, 1042–1049.
- Shattuck, P. T., Roux, A. M., Hudson, L. E., Lounds-Taylor, J., Maenner, M. J., & Trani, J.-F. (2012). Services for adults with an autism spectrum disorder. *Canadian Journal of Psychiatry*, *57*, 284–291.
- Sherbourne, C. D., & Stewart, A. L. (1991). The MOS social support survey. *Social Science & Medicine*, *32*, 705-714.
- Sherman, A. C., & Simonton, S. (2012). Effects of personal meaning among patients in primary and specialized care: Associations with psychosocial and physical outcomes. *Psychology & Health*, *27*, 475–490.
- Shrira, A., Shmotkin, D., Palgi, Y., Soffer, Y., Hamama Raz, Y., Tal-Katz, P., . . . Benight, C. C. (2015). How do meaning in life and positive affect relate to adaptation to stress? The case of firefighters following the Mount Carmel forest fire. *The Israel Journal of Psychiatry and Related Sciences*, *52*, 68–70.
- Silva, L. M., & Schalock, M. (2012). Autism parenting stress index: Initial psychometric evidence. *Journal of Autism and Developmental Disorders*, *42*, 566-574.
- Singer, G. H. S. (2006). Meta-analysis of comparative studies of depression in mothers of children with and without developmental disabilities. *American Journal on Mental Retardation*, *111*, 155–169.
- Smith, L. E., Greenberg, J. S., & Seltzer, M. M. (2012). Social support and well-being at mid-life among mothers of adolescents and adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *42*, 1818–1826.
- Smith, L. E., Hong, J., Seltzer, M. M., Greenberg, J. S., Almeida, D. M., & Bishop, S. L. (2010). Daily experiences among mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *40*, 167-178.

- Smith, L. E., Seltzer, M. M., & Greenberg, J. S. (2012). Daily health symptoms of mothers of adolescents and adults with fragile X syndrome and mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 42*, 1836-1846.
- Smith, G. C., & Tobin, S. S. (1990). Permanency planning among older parents of adults with lifelong disabilities. *Journal of Gerontological Social Work, 14*, 35–59.
- Smith, G. C., Tobin, S. S., & Fullmer, E. M. (1995). Elderly mothers caring at home for offspring with mental retardation: A model of permanency planning. *American Journal on Mental Retardation, 99*, 487–499.
- Soper, D.S. (2018). A-priori Sample Size Calculator for Structural Equation Models [Software]. Available from <http://www.danielsoper.com/statcalc>
- Sorkin, D., Rook, K. S., & Lu, J. L. (2002). Loneliness, lack of emotional support, lack of companionship, and the likelihood of a having heart condition in an elderly sample. *Annals of Behavioral Medicine, 24*, 290-298.
- Steger, M. F., Frazier, P., Oishi, S., & Kaler, M. (2006). The meaning in life questionnaire: Assessing the presence of and search for meaning in life. *Journal of Counseling Psychology, 53*, 80–93.
- Strough J., Bruine, de Bruin, W., Parker, A.M., Lemaster, P., Pichayayothin, N., & Delaney, R. (2016). Hour glass half-full or half-empty? Future time perspective and preoccupation with negative events across the life span. *Psychology and Aging, 31*, 558–573.
- Stuart, M., & McGrew, J. H. (2009). Caregiver burden after receiving a diagnosis of an autism spectrum disorder. *Research in Autism Spectrum Disorders, 3*, 86–97.
- Tabachnick, B. & Fidell, L. (2013). *Using multivariate statistics*. Boston: Pearson Education.
- Taylor, J. L., Henninger, N. A., & Mailick, M. R. (2015). Longitudinal patterns of employment and postsecondary education for adults with autism and average-range IQ. *Autism, 19*, 785–793.
- Taylor, J. L., & Seltzer, M. M. (2011). Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. *Journal of Autism and Developmental Disorders, 41*, 566–574.
- VanBergeijk, E., Klin, A., Volkmar, F. (2008). Supporting more able student on the autism spectrum: College and beyond. *Journal of Autism and Developmental Disorders, 38*, 1359–1370.

- Van Bourgondien, M. E., Dawkins, T., & Marcus, L. (2014). Families of adults with autism spectrum disorders. In F.R. Volkmar, B. Reichow, & J.C. McPartland (Eds.) *Adolescents and adults with autism spectrum disorders* (15-40). New York: Springer.
- Volkmar, F.R., Reichow, B., & McPartland, J.C. (2014). Autism spectrum disorder in adolescents and adults: An introduction. In F.R. Volkmar, B. Reichow, & J.C. McPartland (Eds.) *Adolescents and adults with autism spectrum disorders* (1-13). New York: Springer.
- Volkmar, F.R., Reichow, B., Westphal, A., & Mandell, D.S. (2013). Autism and the autism spectrum: Diagnostic concepts. In F.R. Volkmar, S.J. Rogers, R. Paul, & K.A. Pelphrey (Eds.) *Handbook of autism and pervasive developmental disorders* (3-27). Hoboken, NJ: Wiley.
- Wang, Y. A., & Rhemtulla, M. (2020). Power analysis for parameter estimation in structural equation modeling: A discussion and tutorial. In press at *Advances in Methods and Practices in Psychological Science*.
- Ware, J.E., Kosinski, M., & Keller, S. (1994). SF-36 physical and mental health summary scales: A user's manual. Boston, MA: New England Medical Center.
- Ware, J. E., & Sherbourne, C. D. (1992). The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. *Medical Care*, 30, 473-483.
- Watkins, D.C. (2017). Rapid and rigorous qualitative data analysis: The “RADaR” technique for applied research. *International Journal of Qualitative Methods*, 16, 1-9.
- Watson, S., Hayes, S., Radford-Paz, E., & Coons, K. (2013). “I’m hoping, I’m hoping...”: Thoughts about the future from families of children with autism or fetal alcohol spectrum disorder in Ontario. *Journal on Developmental Disabilities*, 19, 76-93.
- Weiss, D., & Lang, F. R. (2012). “They” are old but “I” feel younger: Age-group dissociation as a self-protective strategy in old age. *Psychology and Aging*, 27, 153–163.
- Weiss J. A., Tint A., Paquette-Smith, M. & Lunsky Y. (2016). Perceived self-efficacy in parents of adolescents and adults with autism spectrum disorder. *Autism*, 20, 425-434.
- Westland, J. C. (2010). Lower bounds on sample size in structural equation modeling. *Electronic Commerce Research and Applications*, 9, 476-487.
- Weston, R., & Gore, P. A. (2006). A brief guide to structural equation modelin. *The Counseling Psychologist*, 34, 719-751.

- Williams, T. V., Hartmann, K., Paulson, J. F., Raffaele, C. T., & Urbano, M. R. (2019). Life after an autism spectrum disorder diagnosis: A comparison of stress and coping profiles of African American and Euro-American caregivers. *Journal of Autism and Developmental Disorders, 49*, 1024–1034.
- Willis, G.B. (2005). *Cognitive interviewing: A tool for improving questionnaire design*. Thousand Oaks, CA: Sage.
- Willis, G.B., & Artino, A.R. (2013). What do our respondents think we're asking? Using cognitive interviews to improve medical education surveys. *Journal of Graduate Medical Education, 353-356*.
- Zimbardo, P. G., & Boyd, J. N. (1999). Putting time in perspective: A valid, reliable individual-differences metric. *Journal of Personality and Social Psychology, 77*, 1271–1288.

APPENDIX A
ACCUMULATED STRESSORS SCALE (PHASE 1)

Below are possible experiences related to parenting an individual with ASD. Please indicate if you have (“YES”) or have not (“NO”) experienced these.

Please answer questions 1-8 considering experiences across time (since childhood to present time).

	YES 1	NO 2
Future Planning: Childhood to Current		
1. Considered who will provide care when you are no longer able to		
2. Considered your child’s future in terms of residence, employment, and general lifestyle		
3. Actively engaged in future planning decisions (including but not limited to guardianship, letter of intent, financial planning, etc.)		
4. Lack adequate or understandable information about future planning		
Self-Care and Social Support: Childhood to Current		
5. Involvement in your own personal activities/events less than desired due to aspects of caregiving (e.g., hobbies, clubs)		
6. Unable to obtain relief from caregiving		
7. Time spent with family and/or friends less than desired due to aspects of caregiving		
8. Social exclusion or loss of social supports		

Please answer questions 9-16 only considering experiences you have had since your child with ASD entered adulthood (age 18 to present time).

	YES 1	NO 2
Aspects of Young Adulthood Transition: Current		

9. Navigating new entitlement system/services		
10. Loss of entitlements/services		
11. Balancing autonomy and involvement/support		
12. Determining appropriate living situation		
Services and Unmet Needs: Current		
13. Appropriate ASD adult services and/or interventions are available		
14. More services for my adult are needed (including but not limited to employment services, day programs, etc.)		
15. Unable to obtain desired services due to adult's level of functioning		
16. Lack of social outlets for my adult child		

APPENDIX B
COGNITIVE INTERVIEW

ID: _____ Date: _____ Start Time: _____ Stop Time: _____ Interview Recorded: Y N

Thank you for participating in this cognitive interview! Your feedback and insights will help to ensure that items on this survey are meaningful to the population of parents of adults with autism before the survey is actually administered, and will allow me to modify, clarify, or augment questions in order to fit with my objectives. The purpose of this interview is to find out what you think about one survey measure related to accumulated stressors for parents of adults with autism. It is estimated that this will take 30 minutes to one hour.

As you recall, I will be audio recording the interview. Do I have your permission to do so?

If YES, start the recorder and review the consent form to the participant.

If NO, review the consent form to the participant. If they are still unwilling to be audio recorded inform them of this requirement and thank them for their time.

Now we will review the informed consent... Do you have any questions?

I will need to obtain verbal consent whether you agree or do not agree to participate in the current study.

Before we start the survey, I have some brief questions about you and your child with autism.

1. What is your age?

40-49 50-59 60-69 70-79 80-89 90-99

2. With which race do you identify? (Select all that apply)

African American or Black American Indian or Alaska Native
 Asian or Asian American Hispanic or Latinx Middle Eastern
 Pacific Islander White or Caucasian A race not listed, specify: _____
 Prefer not to respond

3. With which gender do you identify? (Select all that apply)

Woman Man Transgender Non-binary
 Genderqueer or gender nonconforming An identity not listed, specify: _____
 Prefer not to respond

These next questions are about your child with autism.

1. What is their age? _____
2. With which race do they identify? (Select all that apply)
 - _____ African American or Black _____ American Indian or Alaska Native
 - _____ Asian or Asian American _____ Hispanic or Latinx _____ Middle Eastern
 - _____ Pacific Islander _____ White or Caucasian _____ A race not listed, specify: _____
 - _____ Prefer not to respond
3. With which gender do they identify? (Select all that apply)
 - _____ Woman _____ Man _____ Transgender _____ Non-binary
 - _____ Genderqueer or gender nonconforming _____ An identity not listed, specify: _____
 - _____ Don't know/Prefer not to respond
4. What is their primary diagnosis? _____
5. What was the age of their diagnosis? _____
6. What other diagnoses do they have from a medical and/or mental health professional?

Now you will complete a 16-item measure that is intended to measure potential accumulated stressors faced by parents of adults with autism. After you complete the measure, I have some specific questions for you to answer, and then we will make sure to discuss other thoughts you have outside of my specific questions.

If ZOOM, I am going to share my screen for you to see the survey (in Qualtrics). Please read the instructions and each question aloud. Please say your response aloud to each question and I will click the response you indicate. Although we will be addressing specific questions of mine as well as all of your other thoughts after you complete the whole survey, feel free to say anything you're thinking throughout. I will be taking notes throughout this whole process. What questions do you have before we begin?

If PHONE, I am going to email you the Qualtrics survey right now so that you have the survey in front of you to complete. Please read the instructions and each question aloud. Please say your response aloud to each question so that I can indicate your responses on my end. Although we will be addressing specific questions of mine as well as all of your other thoughts after you complete the whole survey, feel free to say anything you're thinking throughout. I will be taking notes throughout this whole process. When you complete the survey don't click submit, because we will want to keep the survey on the screen to talk through afterwards. What questions do you have before we begin?

Parent Accumulated Stressors

Below are possible experiences related to parenting an individual with ASD. Please indicate if you have (“YES”) or have not (“NO”) experienced these.

Please answer questions 1-8 considering experiences across time (since childhood to present time).

	YES 1	NO 2
Future Planning: Childhood to Current		
17. Considered who will provide care when you are no longer able to		
18. Considered your child’s future in terms of residence, employment, and general lifestyle		
19. Actively engaged in future planning decisions (including but not limited to guardianship, letter of intent, financial planning, etc.)		
20. Lack adequate or understandable information about future planning		
Self-Care and Social Support: Childhood to Current		
21. Involvement in your own personal activities/events less than desired due to aspects of caregiving (e.g., hobbies, clubs)		
22. Unable to obtain relief from caregiving		
23. Time spent with family and/or friends less than desired due to aspects of caregiving		
24. Social exclusion or loss of social supports		

Please answer questions 9-16 only considering experiences you have had since your child with ASD entered adulthood (age 18 to present time).

	YES 1	NO 2
Aspects of Young Adulthood Transition: Current		
25. Navigating new entitlement system/services		
26. Loss of entitlements/services		
27. Balancing autonomy and involvement/support		
28. Determining appropriate living situation		
Services and Unmet Needs: Current		

29. Appropriate ASD adult services and/or interventions are available		
30. More services for my adult are needed (including but not limited to employment services, day programs, etc.)		
31. Unable to obtain desired services due to adult's level of functioning		
32. Lack of social outlets for my adult child		

Notes/Observations during survey completion:

-

After participant completes the survey and you have all responses:
Great! I'm eager to hear your thoughts and any questions you may have. First, I have some questions for you. Let's start specifically with items 1-8 (ensure visible on your/their screen).

Questions 1-8

Probes	Response
<i>Paraphrasing Cognitive Probes</i>	
Can you repeat the instructions for questions 1-8 in your own words?	
* Can you tell me in your own words what question ___ was asking?	
<i>Comprehension/Interpretation Cognitive Probes</i>	
What does "actively engaged in" mean to you?	
* How do you understand the word/phrase _____?	
<i>General Cognitive Probes</i>	
Were these questions easy or hard to answer?	
* How did you arrive at ___ answer?	
* I noticed that you hesitated on number ____. Tell me what you were thinking.	

* Tell me more about ____.	
----------------------------	--

* *Potential* probes to use depending on comments, hesitation, nonverbal indications of confusion throughout survey completion

Questions 9-16

Probes	Response
<i>Paraphrasing Cognitive Probes</i>	
Can you repeat the instructions for questions 9-16 in your own words?	
* Can you tell me in your own words what question ____ was asking?	
<i>Comprehension/Interpretation Cognitive Probes</i>	
What does “entitlement/services” mean to you?	
* How do you understand the word/phrase _____?	
<i>Specific Cognitive Probes</i>	
How did you arrive at your answer of ____ for #16?	
* Did you have any trouble with the opposite directionality of #13?	
<i>General Cognitive Probes</i>	
Were these questions easy or hard to answer?	
* How did you arrive at ____ answer?	
* I noticed that you hesitated on number _____. Tell me what you were thinking.	
* Tell me more about _____.	

* *Potential* probes to use depending on comments, hesitation, nonverbal indications of confusion throughout survey completion

Full Measure (Questions 1-16)

Probes	Response
<i>Paraphrasing Cognitive Probes</i>	
Can you repeat the general purpose of the measure in your own words?	
<i>Specific Cognitive Probes</i>	
In your opinion, does the change in time reference in 1-8 from 9-16 make sense?	
<i>General Cognitive Probes</i>	
What changes would you suggest to make the measure better overall (wording, format, add/remove item, etc.)?	

APPENDIX C
ASD COLLEGE TRANSITION/SUPPORT PROGRAMS CONTACTED

1. Autism Spectrum Disorders College Transition and Support Program (UA-ACTS)
The University of Alabama
2. Autism Support Program
University of Arkansas
3. The College Link Program
California State University
4. Comprehensive Autism Program (CAP)
Golden West College
5. Spectrum Scholars
University of Delaware
6. Access Plus
Nova Southeastern University
7. Transition to Healthiness, Resourcefulness, Independence, Vocation, and Education
(THRIVE)
University of North Florida
8. Argos for Autism Program
University of West Florida
9. The Raven Scholars Program
University of Idaho
10. Students with Autism Transitional Education Program (STEP)
Eastern Illinois University
11. Transition Autism Program (TAP)
Harper College
12. The Autism Program at Ancilla College (APAC)
Ancilla College
13. Autism Resources for Career and Higher Education (ARCH)

Loras College

14. Kelly Autism Program (KAP)
Western Kentucky University
15. Bridge to Independence
Nicholls State University
16. College Supports Program (CSP)
Eastern Michigan University
17. Autism Liaison Services
Mississippi State University
18. COMPASS Program
Fairleigh Dickinson University (Metro Campus & Florham Campus)
19. ENHANCE Program
Ramapo College of New Jersey
20. College Support Program (CSP)
Rutgers University
21. College Autism Transition Support (CATS) Program
Daemen College
22. Pathways And Connections (PAC) Program
Manhattanville College
23. Cornerstone Program
Purchase College, SUNY
24. Spectrum Support Program
Rochester Institute of Technology
25. ASD Affinity Program
Defiance College
26. Autism Spectrum Peer Coaching Team (ASPeCT)
Ohio University
27. Autism College Experience (ACE!)
The Ohio State University
28. Raiders on the Autism Spectrum Excelling (RASE)

Wright State University

29. X-Path Program
Xavier University
30. Neill-Wint Center for Neurodiversity
University of Science and Arts of Oklahoma
31. Drexel Autism Support Program (DASP)
Drexel University
32. College Success Program (CSP)
Eastern University
33. Boro Autism Support Initiative for Success (BASIS) Program
Edinboro University
34. Labyrinth Center
Indiana University of Pennsylvania
35. My Place
Kutztown University
36. Autism Initiative at Mercyhurst (AIM) Program
Mercyhurst University
37. Autism Transitions for Learning Achievement and Support (ATLAS)
Slippery Rock University
38. Kinney Center ASPIRE Program
St. Joseph's University
39. Dub-C Autism Program (D-CAP)
West Chester University
40. Spectrum Program
Clemson University
41. Strong Program
Dakota State University
42. Full Spectrum Learning (FSL) Program
Austin Peay State University
43. Mosaic

- University of Tennessee Chattanooga
44. Connecting to College (CtC) Program
University of Houston-Clear Lake
 45. Mason Autism Support Initiative (MASI)
George Mason University
 46. College Program for Students with Autism Spectrum Disorder
Marshall University
 47. On Your Marq
Marquette University
 48. SNC ASD Support Program
St. Norbert College
 49. Student Opportunities for Career, Independent Living, and Academic Life (SOCIAL
Gators)
University of Florida
 50. BUILD Program
University of Indianapolis
 51. Activate Program
Merrimack College
 52. Mentoring, Organization, and Social Support for Autism/All Inclusion on Campus
(MOSSAIC) Program
University of Montana
 53. NYU Connections ASD Program
New York University
 54. Supported Academics and Independent Living Services (SAILS)
Seattle Central College
 55. Project CASE
Tech University
 56. Autism Services Center
Western Michigan University
 57. Bridges to Adelphi Program

Adelphi University

58. College Access Navigators (CAN)
Willamette University

59. Neurodiversity Navigators
Bellevue College

60. BOND Program
Michigan State University

61. PLUS Program
Muskingum University

62. Pathfinders Program
University of Tulsa

63. College Assistance Program (CAP)
Iona College

64. Autism Advocates Program & Partnering for Achievement and Learning Success (PALS)
Kent State University

65. Oasis Program
Pace University

66. Social Interaction Group Network for ALL (SIGNA)
University of Maryland

APPENDIX D
ACCUMULATED STRESSORS SCALE (PHASE 2)

Below are possible experiences related to parenting an individual with ASD.

Have you EVER experienced these things (since your child’s childhood to present time)?

Please indicate "yes" if you have, or "no" if you have not experienced these. Select both "yes" options IF you have had this experience during BOTH timeframes.

	Yes- During their childhood/adolescence (before age 18)	Yes- During their adulthood (age 18 to present time)	No
1. Considered who will provide care when you are no longer able to	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Considered your child’s future in terms of residence, employment, and general lifestyle	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Actively engaged in future planning decisions (including but not limited to guardianship, letter of intent, financial planning, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Lacked adequate or understandable information about future planning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Involvement in your own personal activities/events (e.g., hobbies, clubs) less than desired due to aspects of caregiving	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Unable to obtain relief from aspects of caregiving	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Time spent with family and/or friends less than desired due to aspects of caregiving	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Social isolation, or exclusion, or loss of social supports	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Item 1

[If childhood/adolescence only]

Q1 You indicated considering who will provide care when you are no longer able to when your child was under 18. Was this a stressor?

- Yes
- No

[If adulthood only]

Q1 You indicated considering who will provide care when you are no longer able to when your child was an adult. Is this a stressor?

- Yes
- No

[If both childhood and adulthood]

Q1 You indicated considering who will provide care when you are no longer able to when your child was under 18 and during adulthood. Has this been

- A stressor only during childhood/adolescence
- A stressor only during adulthood
- A stressor both during childhood/adolescence and adulthood
- Not a stressor in either childhood/adolescence or adulthood

Item 2

[If childhood/adolescence only]

Q2 You indicated considering your child's future in terms of residence, employment, and general lifestyle when your child was under 18. Was this a stressor?

- Yes
- No

[If adulthood only]

Q2 You indicated considering your child's future in terms of residence, employment, and general lifestyle when your child was an adult. Is this a stressor?

- Yes
- No

[If both childhood and adulthood]

Q2 You indicated considering your child's future in terms of residence, employment, and general lifestyle when your child was under 18 and during adulthood. Has this been

- A stressor only during childhood/adolescence
- A stressor only during adulthood
- A stressor both during childhood/adolescence and adulthood
- Not a stressor in either childhood/adolescence or adulthood

Item 3

[If childhood/adolescence only]

Q3 You indicated actively engaging in future planning decisions (including but not limited to guardianship, letter of intent, financial planning, etc.) when your child was under 18. Was this a stressor?

- Yes
- No

[If adulthood only]

Q3 You indicated actively engaging in future planning decisions (including but not limited to guardianship, letter of intent, financial planning, etc.) when your child was an adult. Is this a stressor?

- Yes
- No

[If both childhood and adulthood]

Q3 You indicated actively engaging in future planning decisions (including but not limited to guardianship, letter of intent, financial planning, etc.) when your child was under 18 and during adulthood. Has this been

- A stressor only during childhood/adolescence
- A stressor only during adulthood
- A stressor both during childhood/adolescence and adulthood
- Not a stressor in either childhood/adolescence or adulthood

Item 4

[If childhood/adolescence only]

Q4 You indicated lacking adequate or understandable information about future planning when your child was under 18. Was this a stressor?

- Yes
- No

[If adulthood only]

Q4 You indicated lacking adequate or understandable information about future planning when your child was an adult. Is this a stressor?

- Yes
- No

[If both childhood and adulthood]

Q4 You indicated lacking adequate or understandable information about future planning when your child was under 18 and during adulthood. Has this been

- A stressor only during childhood/adolescence
- A stressor only during adulthood
- A stressor both during childhood/adolescence and adulthood
- Not a stressor in either childhood/adolescence or adulthood

Item 5

[If childhood/adolescence only]

Q5 You indicated involvement in your own personal activities/events (e.g., hobbies, clubs) less than desired due to aspects of caregiving when your child was under 18. Was this a stressor?

- Yes
- No

[If adulthood only]

Q5 You indicated involvement in your own personal activities/events (e.g., hobbies, clubs) less than desired due to aspects of caregiving when your child was an adult. Is this a stressor?

- Yes
- No

[If both childhood and adulthood]

Q5 You indicated involvement in your own personal activities/events (e.g., hobbies, clubs) less than desired due to aspects of caregiving when your child was under 18 and during adulthood. Has this been

- A stressor only during childhood/adolescence
- A stressor only during adulthood
- A stressor both during childhood/adolescence and adulthood
- Not a stressor in either childhood/adolescence or adulthood

Item 6

[If childhood/adolescence only]

Q6 You indicated being unable to obtain relief from aspects of caregiving when your child was under 18. Was this a stressor?

- Yes
- No

[If adulthood only]

Q6 You indicated being unable to obtain relief from aspects of caregiving when your child was an adult. Is this a stressor?

- Yes
- No

[If both childhood and adulthood]

Q6 You indicated being unable to obtain relief from aspects of caregiving when your child was under 18 and during adulthood. Has this been

- A stressor only during childhood/adolescence
- A stressor only during adulthood
- A stressor both during childhood/adolescence and adulthood
- Not a stressor in either childhood/adolescence or adulthood

Item 7

[If childhood/adolescence only]

Q7 You indicated time spent with family and/or friends less than desired due to aspects of caregiving when your child was under 18. Was this a stressor?

- Yes
- No

[If adulthood only]

Q7 You indicated time spent with family and/or friends less than desired due to aspects of caregiving when your child was an adult. Is this a stressor?

- Yes
- No

[If both childhood and adulthood]

Q7 You indicated time spent with family and/or friends less than desired due to aspects of caregiving when your child was under 18 and during adulthood. Has this been

- A stressor only during childhood/adolescence
- A stressor only during adulthood
- A stressor both during childhood/adolescence and adulthood
- Not a stressor in either childhood/adolescence or adulthood

Item 8

[If childhood/adolescence only]

Q8 You indicated experiencing social isolation, or exclusion, or loss of social supports when your child was under 18. Was this a stressor?

- Yes
- No

[If adulthood only]

Q8 You indicated experiencing social isolation, or exclusion, or loss of social supports when your child was an adult. Is this a stressor?

- Yes
- No

[If both childhood and adulthood]

Q8 You indicated experiencing social isolation, or exclusion, or loss of social supports when your child was under 18 and during adulthood. Has this been

- A stressor only during childhood/adolescence
- A stressor only during adulthood
- A stressor both during childhood/adolescence and adulthood
- Not a stressor in either childhood/adolescence or adulthood

Below are possible experiences related to parenting an individual with ASD.

Have you experienced these things since your child with ASD entered adulthood (age 18 to present time)?

Please indicate "yes" if you have, or "no" if you have not experienced these.

	Yes	No
1. Navigating new systems/services for adults (e.g., vocational rehab, supported employment, mental health, disability services, other agencies)	<input type="radio"/>	<input type="radio"/>
2. Loss of entitlements, services, or resources	<input type="radio"/>	<input type="radio"/>
3. Balancing their autonomy and my involvement/support	<input type="radio"/>	<input type="radio"/>
4. Determining appropriate living situation	<input type="radio"/>	<input type="radio"/>
5. Appropriate adult ASD services and/or interventions are not available	<input type="radio"/>	<input type="radio"/>
6. More services for my adult are needed (including but not limited to employment, mental health, life skills services, day programs, etc.)	<input type="radio"/>	<input type="radio"/>
7. Unable to obtain desired services due to adult's level of functioning	<input type="radio"/>	<input type="radio"/>
8. Lack of social outlets for my adult child	<input type="radio"/>	<input type="radio"/>

You indicated you have experienced the following at some point during your child's adulthood (age 18 to present time). Of these experiences you have had, please select all experiences that were stressors for you:

- Navigating new systems/services for adults (e.g., vocational rehab, supported employment, mental health, disability services, other agencies) (1)
- Loss of entitlements, services, or resources (2)
- Balancing their autonomy and my involvement/support (3)
- Determining appropriate living situation (4)
- Appropriate adult ASD services and/or interventions are not available (5)
- More services for my adult are needed (including but not limited to employment, mental health, life skills services, day programs, etc.) (6)
- Unable to obtain desired services due to adult's level of functioning (7)
- Lack of social outlets for my adult child (8)

APPENDIX E
IRB APPROVAL LETTERS



March 30, 2021

Monica Scicolone, M.A.
Department of Psychology
College of Arts and Sciences
Box 870348

Re: IRB # 20-11-4105: "Quality and Meaning in Life Among Parents of Adults with Autism Spectrum Disorder"

Dear Ms. Scicolone,

The University of Alabama Institutional Review Board has granted approval for your proposed research. Your application has been given expedited approval according to 45 CFR 46. You have also been granted a waiver of written documentation of consent. Approval has been given under expedited review category 7 as outlined below:

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

The approval for your application will lapse on March 29, 2022. If your research will continue beyond this date, please submit the annual report to the IRB as required by University policy before the lapse. Please note, any modifications made in research design, methodology, or procedures must be submitted to and approved by the IRB before implementation. Please submit a final report form when the study is complete.

Please use reproductions of the IRB-approved informed consent form to obtain consent from your participants.

Sincerely,

Carpantato T. Myles, MSM, CIM, CIP, EXCS™
Director & Research Compliance Officer

cc: Dr. Patricia Parmelee

December 3, 2021

Monica Scicolone, MA
Department of Psychology
College of Arts & Sciences
The University of Alabama
Box 870348

Re: IRB # 20-11-4105-A: "Quality and Meaning in Life Among Parents of Adults with Autism Spectrum Disorder"

Dear Ms. Scicolone:

The University of Alabama Institutional Review Board has reviewed the revision to your previously approved expedited protocol. The board has approved the change in your protocol.

Please remember that your protocol will expire on March 29, 2022.

Should you need to submit any further correspondence regarding this proposal, please include the assigned IRB application number. Changes in this study cannot be initiated without IRB approval, except when necessary to eliminate apparent immediate hazards to participants.

Good luck with your research.

Sincerely,

Carpantato T. Myles, MSM, CIM, CIP
Director & Research Compliance Officer

March 23, 2022

Monica Scicolone, M.A.
Department of Psychology
College of Arts and Sciences
The University of Alabama
Box 870348

Re: IRB # 20-11-4105-R1 "Quality and Meaning in Life Among Parents of Adults with Autism Spectrum Disorder"

Dear Ms. Scicolone:

The University of Alabama Institutional Review Board has granted approval for your renewal application. Your renewal application has been given expedited approval according to 45 CFR part 46. You have also been granted the requested waiver of documentation of informed consent. Approval has been given under expedited review category 7 as outlined below:

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

The approval for your application will lapse on March 22, 2023. If your research will continue beyond this date, please submit a continuing review to the IRB as required by University policy before the lapse. Please note, any modifications made in research design, methodology, or procedures must be submitted to and approved by the IRB before implementation. Please submit a final report form when the study is complete.

Please use reproductions of the IRB approved informed consent form to obtain consent from your participants.

Good luck with your research.

Sincerely,

T. Myles
Carpantato T. Myles, MSM, CIM, CIP
Director & Research Compliance Officer