

THE IMPACT OF A CHILD'S AUTISM DIAGNOSIS ON CAREGIVER
GRIEF EXPERIENCES AND ISOLATION

by

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DEDICATION

This work is dedicated to all caregivers who currently are or have raised children with autism. I hope this work sheds light on your everyday experiences and provides reassurance that you are not alone in your journey.

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ABSTRACT

Raising a child with autism presents caregivers with a unique set of experiences. Previous research suggests that caregivers in this population experience grief, isolation, increased stress, and depressive symptoms, however, there is no theoretical model to understand the interrelations between these variables. The current study presents a new theoretical model to test the associations between these constructs to help understand what influences stress and depressive symptoms in caregivers raising a child with ASD. Specifically, the present study hypothesizes that 1) all main variables of interest in the model will be positively related, and that 2) chronic sorrow, social isolation, and existential isolation will serve as mediators in the relationship between uncertainty and both stress and depressive symptoms. A Qualtrics survey was distributed to parents or legal guardians of a child with autism ($n = 156$; $M_{age} = 38.83$; 73.1% female; 82.1% white) through CloudResearch Connect and clinics nationwide. Participants completed six questionnaires assessing uncertainty, chronic sorrow, social isolation, existential isolation, stress, and depressive symptoms. Correlation analyses showed all variables were positively related to each other aside from social isolation which was not related to either chronic sorrow or uncertainty. Mediation analyses showed that chronic sorrow served as a partial mediator in the relationship between uncertainty and stress, and a full mediator in the relationship between uncertainty and depressive symptoms. Social and existential isolation were not found to mediate either the relationship between uncertainty and stress or uncertainty and depressive symptoms. This study had a number of implications including being the first to measure existential isolation, uncertainty, and chronic sorrow in this population. This study provides initial support in understanding the role that chronic sorrow plays in caregiver stress and depressive symptoms, and suggests that, while related to stress and depressive symptoms, social and existential isolation need to be reconceptualized within the model.

INTRODUCTION

Autism spectrum disorder (ASD) is a chronic neurodevelopmental disorder defined by deficits in social communication, behavioral expressions, and abnormal sensory processing (American Psychiatric Association, 2013). Additionally, ASD is a highly prevalent disorder with 1 in 36 children being diagnosed in 2023 (Center for Disease Control, 2024). Symptoms of ASD typically become apparent in infancy and toddlerhood and persistent across the life course (Lord et al., 2000; American Psychiatric Association, 2013). Symptom severity can range from minor deficits in the understanding of social cues (e.g., averting eye contact with others when speaking) to major communication and behavioral deficits (e.g., the absence of verbal language, or the use of self-injurious behaviors when dysregulated; American Psychiatric Association, 2013). In addition, children with ASD often exhibit a strong preference for routine (e.g. eating the same foods or adhering to a strict daily routine), display an absence of social engagement (e.g., not turning towards the speaker when their name is called), and engage in abnormal repetitive (e.g. flapping the hands) and self-injurious (e.g. headbanging) behaviors in response to a stimulus (Lord et al., 2000; American Psychiatric Association, 2013). The symptomology of autism requires caregivers to be extensively involved in their child's care which may have long-term negative implications for both children and their family (Bonis, 2016). It is often difficult to predict when atypical behaviors (e.g. abnormal social engagement, repetitive behaviors) may occur, and the presentation of these behaviors may change over time. Also, the early onset and lifelong nature of ASD necessitates that caregivers will need to manage symptoms indefinitely.

The caregiving experience for those raising a child with ASD is vastly different from the experience of those raising typically developing children. Caregivers may experience unique challenges such as increased uncertainty (Bravo-Benítez et al., 2019), grief (Blaska, 1998), and

social isolation (Pepperell et al., 2018; Samsell et al., 2021). Moreover, studies have shown that caregivers of children with ASD experience a variety of challenges that may lead to the development of stress and depression (Krishnan et al., 2017; Mihandoust et al., 2021; Hamlyn-Wright et al., 2007; Bonis, 2016). Although stress and depression have been widely studied in this population, the relationship between caregivers' experiences and the development of these negative outcomes is not well understood. Previous research has focused on loss of control (Hamlyn-Wright et al., 2007), increased caregiving demands (Bravo-Benítez et al., 2019; Bonis, 2016), and lack of support (Pepperell et al., 2018; Siklos & Kerns, 2006; Wayment & Brookshire, 2017; Devenish et al., 2020; Boyd, 2002; Mihandoust et al., 2021) as potential precursors for the development of negative outcomes among caregivers. However, little is known about other potential correlates, such as repeated cycles of grief, uncertainty about the future (e.g., expectations, responsibilities, long-term outcomes for the child), and social isolation. Therefore, the purpose of this study is to fill the gaps in the current literature, to further investigate this caregiving experience, and how it may lead to the development of stress and depressive symptoms in this population.

UNCERTAIN THOUGHTS AND FEELINGS

Raising a child with ASD redefines a caregiver's role and responsibility to their child, which can raise new concerns on how best to manage their child's emerging set of needs.

Immediately following the child's diagnosis, caregivers are met with a number of decisions to make about their child's care that can have a lasting impact on their developmental trajectory (i.e. learning about and selecting behavior therapy centers or medications and advocating for school-based services; Mihandoust et al., 2021; Samsell et al., 2022; Rabba et al., 2019).

Unfortunately, many caregivers feel uncertain about what resources and services are available to their child and do not feel adequately equipped to make decisions regarding their child's care (Mihandoust et al., 2021; Samsell et al., 2022). This uncertainty can create feelings of inadequacy in caregivers and leads to increased stress and depression in this population (O'Brien, 2007; Bonis, 2016; Batool & Kurshid, 2015; Rabba et al., 2019; Hall & Graff, 2010; Dunn et al., 2001).

In addition, caregivers' face concerns over their child's long-term wellbeing, including uncertainty about their child's developmental trajectory (i.e. will their child ever play on a sports team or maintain fulfilling friendships), and uncertainty about who will care for their child after they die (Fernández-Alcántara et al., 2016). Moreover, the social and behavioral symptoms characteristic of ASD are often unpredictable and may change as time goes on (Olshansky, 1962). The unpredictable nature of ASD symptomology paired with its long term impact on a child's development leaves many caregivers feeling they have little control over the future (Rabba et al., 2019; Dunn et al., 2001; Siman-Tov & Kaniel, 2010). This lack of predictability can be exhausting and may create feelings of stress and depression in caregivers as they feel helpless about how to manage their uncertainty.

Uncertainty is experienced by caregivers in a myriad of ways. Caregivers feel uncertain about how to support their child, how their child's ASD will manifest, and about what their child's future may look like. These uncertain thoughts and feelings extend beyond the diagnosis and succeeding adjustment period to foster a lifelong host of concerns about their child and their wellbeing. In addition to managing uncertain thoughts and feelings about their child, caregivers are simultaneously coming to terms with their own emotionality, an often difficult and exhausting process (Fernández-Alcántara et al., 2016; Bravo-Benítez et al., 2019). Consistent exposure to uncertainty can exacerbate chronic negative caregiver mental health and wellbeing and leaves caregivers longing for the life they had prior to their child's diagnosis. This longing incites distinct grief and isolation experiences unique to this population (Chase, 2022; Cameron et al., 1992; O'Brien, 2007). The next two sections focus on further delineating these two potential consequences of uncertain thoughts and feelings among caregivers as illustrated in the model.

GRIEF AND GRIEVING

Grief is the emotional experience that follows a significant loss (Zisook & DeVaul, 1983; Fernández-Alcántara et al., 2017). Notably, what constitutes a significant loss can vary as some feel grief following the death of a close loved one, known as bereavement grief, while others may experience grief after a breakup or the loss of a job. Previous research has consistently found that caregivers of children with ASD encounter strong feelings of grief following their child's diagnosis (Alimohamadi et al., 2024; Fernández-Alcántara et al., 2016; Bravo-Benítez et al., 2019), and that, for many caregivers, their child's diagnosis felt equitable to the death of the child they expected to raise (Cameron et al., 1992; Fiske 2017; Corcoran et al., 2015; Fernández-Alcántara et al., 2016; Bravo-Benítez et al., 2019; Chase, 2022). Other caregivers, however, grieve differently, longing for the life and flexibility they have prior to their child's diagnosis (Chase, 2022; Cameron et al., 1992; O'Brien, 2007). These studies posit the presence of a unique type of grief that is experienced specifically by caregivers of children with ASD.

Caregivers who have a child with ASD experience a lifelong grief cycle that is similar to but distinct from bereavement grief (Alimohamadi et al., 2024; Fernández-Alcántara et al., 2016; Mitchell & Holdt, 2014; Bravo-Benítez et al., 2019). Similarly to bereavement grief, these caregivers experience the loss of their child, but rather than enduring the physical absence of their child, caregivers are met with the psychological absence of the child they expected to raise (Bravo-Benítez et al., 2019; Fernández-Alcántara et al., 2016). Notably, the origin of this grief is not due to the death of their child but rather the sporadic longing for the return of the child they envisioned raising.

Specifically, cyclical grief (Blaska, 1998) is theorized to be the subset of grief experienced by caregivers of children with ASD. Cyclical grief is the lifelong *recurrence* of

grief-based emotions uniquely experienced by caregivers who have children with disabilities. Blaska's (1998) model suggests the grieving cycle begins with the shattering of a "dream" or ideal expectation of the future for the child, themselves, and their family. In this case, a diagnosis of ASD shatters the caregiver's vision of the child they expected to raise. The reoccurring emotions that follow the shattered "dream" (e.g., disbelief, anxiety, guilt, denial, sadness) occur intermittently throughout varying phases of the family's life (e.g. the family with young children, launching children and moving on, etc.) and hold the caregiver in a lifelong, sporadic grief experience. This theory suggests that the difference between bereavement grief and grief following an ASD diagnosis does not lie in the way or extent to which it is experienced, but rather in the repetitive and subjective nature of their grief experience, something that is not present in bereavement grief.

Previous theory proposes that grief-provoking events may serve as the catalyst of cyclical grief (Krishnan et al., 2017; Bravo-Benítez et al., 2019; Chase, 2022). As a child fails to meet life milestones (e.g. not attending college) or adapts poorly to life changes (e.g. experiencing heightened dysregulation during puberty), caregivers re-experience grief as they are reminded that their child will not fulfill certain anticipated goals due to their ASD (Chase, 2022). Additionally, as caregivers attempt to help their child manage and understand these adjustments in their life, they take on greater caregiving responsibilities, often requiring them to play a more active role in raising their child. While support from caregivers through these transitions is incredibly beneficial for child functioning and adaptation, it leads caregivers to regularly adapt their lives to aid in their child's continued development (Bravo-Benítez et al., 2019; Efstratopoulou et al., 2022). The constant restructuring of schedules and expectations is time-consuming and exhaustive for caregivers. Increased demands and the recurring cycle of grief

experienced by caregivers often leads many to grieve the life they expected to have and the child they expected to raise.

ISOLATION

Another notable loss experienced by caregivers of children with ASD is a loss of social connection with others. Interpersonal relationships and a sense of belonging are crucial to human health, well-being, and adjustment (Baumeister & Leary, 1995). However, as caregivers adjust to raising a child with ASD, they often experience a shift in their priorities, which can lead to their own socialization being neglected. Importantly, for caregivers in this population, social engagement buffers stress, increases optimism, and counters negative family outcomes (Boyd, 2002; Pepperell et al., 2018; Dunn et al., 2001; Siman-Tov & Kaniel, 2011; Hirsch & Paquin, 2019). Specifically, caregivers receiving social support have better adaptation to having a child with ASD (Hamlyn-Wright et al., 2007; Pepperell et al., 2018; Siklos & Kerns, 2006; Wayment & Brookshire, 2017; Devenish et al., 2020; Boyd, 2002), even if those supports are just perceived (Devenish et al. 2020; Siklos & Kerns, 2006). However, even though social interaction appears to mitigate caregiver stress in this population, many still experience difficulty engaging socially, leading to isolation (Cameron et al., 1992; Pepperell et al., 2018; Samsell et al., 2021). Despite the fact that many caregivers claim they would like to have time for socialization with others (Bravo-Benítez et al., 2019), the needs of their child surpass their desire to socialize, thwarting their ability to pursue their own social needs, in turn increasing isolation (Siklos & Kerns, 2006; Boyd, 2002).

There are two types of isolation that caregivers of children with ASD may experience. Subjective isolation is the intrapersonal *feeling* of being absent from others (Nguyen et al., 2020). It is not necessarily a reduction in the level of contact with others, but rather a feeling that one lacks desired social relationships or cannot relate to or connect with others. One specific type of subjective isolation is existential isolation. It is conceptualized as the feeling that others do

not, or cannot, understand one's subjective experiences, leading to a feeling of separation between the self and others (Helm et al., 2019; Pinel et al., 2017). Many caregivers of children with ASD feel that others do not understand or relate to their experience of raising a child with such immense needs (Cameron et al., 1992; Mihandoust et al., 2021; Bonis, 2016), especially given that ASD is a spectrum disorder. ASD symptomology can present in considerably different ways between children, such that two children with the same diagnosis may have differing needs and symptom presentations. For example, a caregiver may be raising a child with ASD who only requires minimal support in social settings, while another may be raising a child who lacks verbal communication and requires 24-hour care. Even though their children have the same diagnosis, these two caregivers would not feel understood by each other because the level of care they each provide their child with is vastly different. The spectrum of ASD presentations exacerbates caregiver existential isolation and leaves them feeling misunderstood and alone in their own caregiving reality.

In contrast, objective isolation is the *quantifiable* reduction in or absence of contact with close others (Nguyen et al., 2020). It differs from subjective isolation in that it is related to the number of connections one has rather than the perceived quality of them. Studies have shown that caregivers of children with ASD have less time available to engage socially due to their busy schedules and the immense level of care they need to provide for their child. These caregiving demands may subsequently increase caregiver objective isolation (O'Brien, 2007; Hall & Graff, 2010; Mihandoust et al., 2021). Collectively, a lack of caregiver socialization can lead to increased subjective and objective isolation in this population, which in turn decreases a caregiver's sense of belonging with family, friends, and community members. This experience

can lead to reduced social adjustment, and increased loneliness and isolation, further inhibiting caregivers from attempting to engage with friends or family.

THE CURRENT STUDY

Caring for a child with ASD is exceedingly taxing for caregivers, often leading to feelings of grief as well as social and existential isolation (Bravo-Benítez et al., 2019; Fernández-Alcántara et al., 2016; Mihandoust et al., 2021; Gray, 2006; Samsell et al., 2022). Exposure to these feelings and experiences may increase stress and depressive symptoms in caregivers raising a child with ASD (Alimohamadi et al., 2024; O'Brien, 2007; Bonis, 2016; Batool & Kurshid, 2015; Rabba et al., 2019; Hall & Graff, 2010; Dunn et al., 2001).

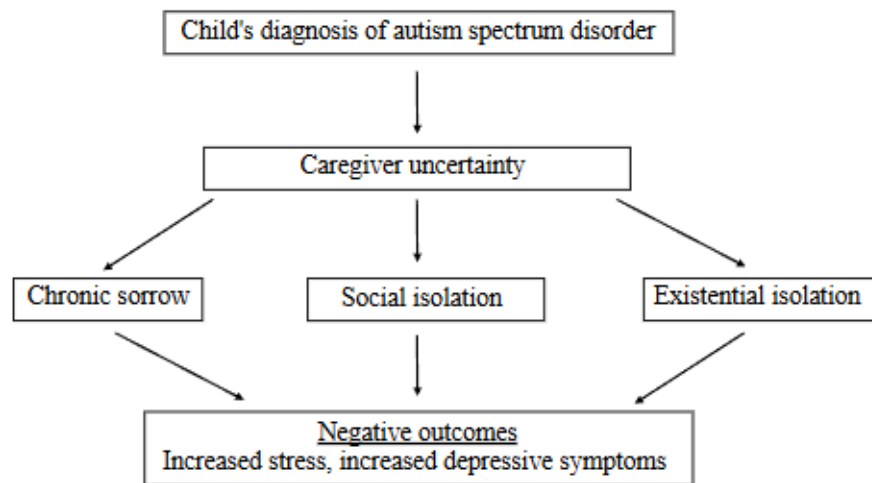


Figure 1: A Theoretical Model of the Impact of an Autism Diagnosis on Caregiver Grief Experiences and Isolation

As shown in Figure 1, following a child's diagnosis with ASD, caregivers are met with initial uncertainty about managing their child's new needs and the future of their family (Alimohamadi et al., 2024; Bravo-Benítez et al., 2019). Uncertain thoughts seemingly remain steadfast throughout caregiver's adjustment to the demands associated with their new caregiving role, and many express concern about how to restructure their life around their child's needs (Bravo-Benítez et al., 2019; Samsell et al., 2022). In turn, uncertain thoughts and feelings may lead caregivers to experience elevated grief and reduced social connectedness. Specifically, they

experience a longing for the life they had prior to their child's diagnosis (Chase, 2022; Cameron et al., 1992; O'Brien, 2007) as well as reduced free time to socialize with others due to increased caregiving demands (Siklos & Kerns, 2006; Boyd, 2002). Previous research postulates that feelings of uncertainty regarding a child's ASD diagnosis increase caregiver grief as many adapt to provide aid to their child while simultaneously mourning the loss of their expected caregiving reality (Bravo-Benítez et al., 2019; Fernández-Alcántara et al., 2016). Grief feelings combined with the permanency of raising a child with ASD can increase caregiver depressive symptoms as it perpetuates a feeling of helplessness in this population (Fernández-Alcántara et al., 2016). Additionally, the cyclical nature of grief in this population (Blaska, 1998) has long been associated with stress as caregivers need to continually adapt to their child's changing developmental and behavioral needs (Olshansky, 1962). The consistent change of caregiving demands diminishes caregivers' confidence in managing their child's ASD as each day brings new challenges with no respite from these responsibilities.

Moreover, uncertain thoughts and feelings can cultivate social isolation experiences for caregivers of children with ASD. Uncertainty about a child's behaviors in public leads many to disengage socially in an effort to avoid unwarranted attention from others (Bonis, 2016; Kinnear et al., 2016; Samsell et al., 2022). Social isolation can lead to caregiver stress and depression as they have no reprieve from their child and their needs (Cameron et al., 1992; Bonis, 2016) and they are not capitalizing on the benefits of social engagement (Baumeister and Leary, 1995). Additionally, caregivers in this population experience a differing caregiving reality from others which leads them to feel emotionally and physically separated from caregivers of typically developing children (Mihandoust et al., 2021; Bonis, 2016). This separation can lead to stress

and depression as caregivers feel unseen in their own reality which calls into question where they stand in the world.

The purpose of this study is to address the gaps in the literature and investigate the relationships between theorized associations in the present model (i.e. caregiver uncertainty, chronic sorrow (as a proxy for cyclical grief), social isolation and existential isolation) and their relationship with the development of negative outcomes (i.e. increased stress and depressive symptoms). Specifically, I aim to investigate the associations between all main variables of interest and test the separate pathways from uncertainty to both stress and depressive symptoms through chronic sorrow, social isolation and existential isolation. I hypothesized that:

1. There would be a significant, positive association between all variables in the model.
2. Cyclical grief (2a), social isolation (2b), and existential isolation (2c) would mediate the relationship between uncertainty and stress.
3. Cyclical grief (3a), social isolation (3b), and existential isolation (3c) would mediate the relationship between uncertainty and depressive symptoms.

METHOD

Power Analysis

I conducted an a priori power analysis utilizing G*Power v. 3.1 (Faul et al., 2007). Results indicated that a minimum of 84 participants were needed to detect a medium effect at the .05 level with a power of .80. Furthermore, I conducted a mediation power analysis using the Monte Carlo Power Analysis for Indirect Effects (*Monte Carlo Power Analysis for Indirect Effects*, n.d.). Results indicated a minimum of 111 participants were needed to detect a medium effect size at the .05 level with a power of .80.

Participants

I recruited participants through autism therapy resources (e.g. clinics, hospitals, and centers; $n = 8$), and CloudResearch Connect ($n = 148$). Clinics, hospitals, and therapy centers were selected for contact if 1) they provide ASD-focused therapy or diagnostics at an in-person location (i.e. a hospital, clinic or center), or 2) they provide ASD-focused therapy or diagnostics in a home setting. Organizations that met the above criteria were contacted by phone or email and asked to distribute the study flyer (Appendix L) and survey to the families they served. Most participants were recruited through CloudResearch Connect (Litman & Robinson, 2021), a recruitment platform that utilizes Amazon's MTurk to contact participants based on specific targets. The targets selected for this study were 1) residents of the United States of America, 2) parents raising 1 or more children, and 3) parents or legal guardians providing care to a child with ASD.

Two hundred and fifty-six caregivers responded to the survey. Caregivers were included in the study if 1) they were parents or legal guardians providing direct care to a child with ASD,

2) they were residents of the United States, 3) the child was 17 years old or younger, 4) they received a diagnosis from a licensed professional (e.g., Licensed Clinical Psychologist, Medical Doctor, Neurologist or Neuropsychologist), and 5) the diagnosis of ASD was provided within the last five years. Data screening indicated that 100 caregivers were ineligible to be included in the study because they did not meet inclusionary criteria ($n = 53$), completed the survey twice ($n = 14$), had a child over the age of 17 ($n = 15$), did not have their child diagnosed by a licensed professional ($n = 12$), did not complete the survey to its fullest extent ($n = 5$), or selected a relationship to the child that was not evidence of legal guardianship ($n = 1$).

One hundred and fifty-six caregivers were thus eligible for the study ($M_{age} = 38.83$, $SD_{age} = 7.58$; 73.1% female; 82.1% white) and included in analyses. Demographic data indicates that caregivers represented diverse racial/ethnic backgrounds (82.1% White, 10.9% Black or African American, 7.1% Hispanic or Latino, 3.2% Asian, Asian American or Pacific Islander, 3.2% Native American or Alaskan Native), gender identities (73.1% female, 25.0% male, 1.9% non-binary or gender non-conforming), and socioeconomic statuses ($M_{SES} = 4.82$, $SD_{SES} = 1.73$). Additional caregiver demographic information can be found in Table 1.

Measures

Demographic Information.

Caregivers provided responses to a series of demographic questions about their gender, race, and socioeconomic background as well as their child's background (see Appendix B, Appendix C). Socioeconomic status was measured using MacArthur's Scale of Subjective Social Status (Adler et al., 2000). MacArthur's Scale of Subjective Social Status is a 1 item self-report scale in which caregivers indicate their access to resources and money on a 1 to 10 scale, with higher scores indicating greater access (see Appendix C). Caregivers also provided diagnostic

Demographic	Frequency	Percentage
Marital Status		
Married	112	71.8
Single	15	9.6
Partnered	13	8.3
Divorced	9	5.8
Separated	5	3.2
Widowed	1	.6
Relationship to Child		
Biological mother	103	66.0
Biological father	33	21.2
Adoptive Mother	8	5.1
Adoptive Father	4	2.6
Grandmother	3	1.9
Aunt	2	1.3
Other	3	1.9
Caring for other Children		
Yes	98	62.8
No	58	37.2
Caring for 2+ Children with ASD		
Yes	20	12.8
No	76	48.7

Table 1. Caregiver Demographic Information

information about their child's ASD diagnosis including how many years ago their child was diagnosed with ASD and who diagnosed their child.

Parents' Uncertainty regarding their Child with Acute Illness Scale.

The Parents' Uncertainty regarding their Child with Acute Illness Scale (PUCAS; Ueki et al., 2017) is a 25-item self-report instrument that measures the level of parent uncertainty about their child's illness (see Appendix D). The PUCAS consists of 5 sections that measure unpredictability and ambiguity around the illness, level of management of their child's illness, interactions with healthcare professionals, and their level of education about the illness. This measure was selected for its focus on caregivers raising a child with a chronic illness and was utilized to assess caregiver uncertainty through a variety of lenses (e.g. level of uncertainty around care for the child, uncertainty around the diagnosis, uncertainty in understanding the illness etc.). Parents were asked to retrospectively rate their level of agreement with each statement at the time of their child's diagnosis. The PUCAS utilizes a 1 (strongly disagree) to 5 (strongly agree) Likert-type scale with higher scores indicating greater uncertainty. Additionally, this measure was adapted to reflect language that better represented the population. As such, the use of the word "illness" was changed to "mental health condition". Additionally, certain items irrelevant to ASD were removed (e.g. 'I cannot imagine what life after recuperation will be like'). Initial reliability and validity studies indicate that the PUCAS has strong overall internal consistency ($\alpha = .92$), strong construct validity (inter-item correlations ranged from $r = .32$ to $r = .73$), and strong criterion validity with the State Anxiety Form, Trait Anxiety Form, and the tension-anxiety, depression, and confusion subscales of the Short Form of the Profile of Mood States (Ueki et al., 2017). Additionally, reliability tests using McDonalds omega (Hayes et al., 2020) indicate that the PUCAS possesses strong reliability in the current study ($\Omega = .90$).

Kendall's Chronic Sorrow Instrument.

Kendall's Chronic Sorrow Instrument (KCSI; Kendall, 2005) is an 18-item self-report instrument that measures chronic sorrow in caregivers who experience ongoing loss (see Appendix E). This questionnaire was adapted to this population to reflect chronic sorrow about a child's diagnosis of ASD. As such, the wording of the KCSI was changed to reflect a diagnosis rather than a loss (e.g.: "I think about the *diagnosis* as if it just happened" vs "I think about the *loss* as if it just happened"). This measure was utilized to assess chronic sorrow and was used in the absence of an empirically tested cyclical grief scale. Chronic sorrow is the emotional experience of profound, persistent sadness, and has been found to be a similar construct to cyclical grief (Olshansky, 1962; Bravo-Benítez et al., 2019). Caregivers were asked to rate the frequency in which they currently feel sorrow for each item from a 0 (Almost never) to 6 (Almost always) Likert-type scale, with higher scores reflecting higher levels of chronic sorrow (Kendall, 2005; Batchelor, 2017). The KCSI is an empirically validated measure displaying excellent reliability ($\alpha = .91$; Kendall, 2005) as well as strong construct validity when compared to the Center for Epidemiologic Studies-Depression Scale and the General Well Being Scale. (Batchelor, 2017). Additionally, reliability tests using McDonalds omega (Hayes et al., 2020) indicate that the KCSI possesses strong reliability in the current study ($\Omega = .94$).

Social Isolation Index.

The Social Isolation Index (Steptoe et al., 2013) is a five item self-report instrument that measures the number of relationships one has (see Appendix F). This questionnaire was selected to measure social isolation as it focuses on the number and frequency of social relationships and interactions that one has with important others. Caregivers were asked to denote the frequency of contact they have with important others on a 1 (Less than monthly) to 5 (More than once a week)

Likert-type scale. Caregivers were also asked to denote their marital status and participation in clubs or organizations with a “Yes” or “No” (i.e. “Yes, I am married to/cohabitating with a partner” or “No, I am not married to/cohabitating with a partner”). Caregivers were assigned a “1” for each “Less than monthly” or “No” response, and a “0” for all other responses. Scores were summed and higher scores indicated greater social isolation (Steptoe et al., 2013). Though reliability and validity statistics are not mentioned in the original study, this measure has been widely used in empirical studies and has been distributed in large, global studies.

Existential Isolation Scale.

The Existential Isolation Scale (EIS; Pinel et al., 2017) is a six item self-report instrument used to assess existential isolation (see Appendix G). This questionnaire was selected because it assesses one’s experiences and perspectives relative to others. Caregivers were asked to rate their current level of agreement with each item on a 0 (strongly disagree) to 9 (strongly agree) Likert-type scale, with higher scores indicating greater levels of existential isolation. Studies found that the EIS demonstrated strong internal consistency overall ($\alpha = .81$), good internal consistency of both existential isolation ($\alpha = .78$), and existential connectedness ($\alpha = .76$) factors, and strong reliability ($r(144) = .78$; Pinel et al., 2017). Additionally, the EIS has demonstrated strong criterion validity as it is positively correlated with alienation ($r = .32$), loneliness ($r = .34$), existential loneliness ($r = .28$), and interpersonal dependency ($r = .23$; Pinel et al., 2017). Additionally, reliability tests using McDonalds omega (Hayes et al., 2020) indicate that the EIS possesses strong reliability in the current study ($\Omega = .91$).

Patient Health Questionnaire – 8.

The Patient Health Questionnaire (PHQ-8; Kroenke et al., 2009) is an eight item self-report instrument that measures depressive symptoms (see Appendix H) and was used to assess

caregiver depressive symptoms as a potential negative outcome. Caregivers were asked to rate how often they currently experience each item using a 0 (Not at all) to 3 (Nearly every day) Likert-type scale, with higher scores indicated more depressive symptoms. Studies demonstrate that the PHQ-8 possesses strong internal reliability ($\alpha = .89$; Shin et al., 2019), and strong convergent validity with the Hamilton Depression Rating Scale ($r = .62$; Shin et al., 2019). Additionally, reliability tests using McDonalds omega (Hayes et al., 2020) indicate that the PHQ-8 possesses strong reliability in the current study ($\Omega = .91$).

Kingston Caregiver Stress Scale.

The Kingston Caregiver Stress Scale (KCSS; Hopkins & Kilik, 2016) is a 10-item self-report instrument that measures level of caregiver stress (see Appendix I) and was used to assess caregiver stress as a potential negative outcome. Caregivers were asked to rate the extent to which they currently felt stress in their caregiving role, family environment, and financial environment using a 1 (Feeling NO stress) to 5 (Extreme Stress) Likert-Type scale, with higher scores representing greater stress (Hopkins & Kilik, 2005). Studies found the KCSS to possess a strong overall reliability ($\alpha = .90$) as well as strong reliability in both the caregiving ($\alpha = .87$) and family and financial ($\alpha = .89$) subscales (Iacob et al., 2021). The KCSS also demonstrated good predictive validity of both depression ($R^2 = .12$) and anxiety ($R^2 = .06$; Iacob et al., 2021). Additionally, reliability tests using McDonalds omega (Hayes et al., 2020) indicate that the KCSS possesses strong reliability in the current study ($\Omega = .90$).

Procedures

The Institutional Review Board at Montana State University (IRB# 2024-1819) reviewed and approved all study procedures. Caregivers who elected to participate were provided with a

Qualtrics survey link through a QR code on the study flyer, or through a direct link on CloudResearch Connect. The first page of the survey detailed the study and provided caregivers with an informed consent statement. Caregivers had to indicate their consent to participate by checking the 'Yes' box. If caregivers selected the 'No' box, they were thanked for their time and redirected out of the survey. Following the consent statement, caregivers were asked to respond to three items targeting inclusionary criteria. Caregivers that met all inclusionary criteria were directed to the main survey which consisted of 97 total items. The child and caregiver demographic sections were presented first, and all succeeding measures were presented in a random order to minimize order effects. At the conclusion of the study, caregivers were provided a debriefing form and list of resources (Appendix K) prior to receiving payment information. Caregivers who participated through CloudResearch were redirected to the CloudResearch platform to receive payment directly from the website, while those recruited from clinics or other therapy centers were directed to a secondary survey which prompted caregivers to include their email address if they wish to be entered into an Amazon gift card drawing.

STATISTICAL ANALYSES

All analyses were conducted in SPSS v. 29. I calculated bivariate Pearson correlations to test hypothesis 1 that all study variables would be positively correlated. I also conducted six simple mediation analyses utilizing SPSS PROCESS and bootstrapping methods (Hayes, 2009) to test hypotheses 2 and 3 (see Figure 2). Uncertainty served as my independent variable in all mediation analyses. In each separate mediation analysis, chronic sorrow, social isolation, or existential isolation served as mediating variables, and either stress or depression served as the dependent variable. Bootstrapped 95% confidence intervals ($n = 5000$) were calculated for each indirect effect (a path coefficient X b path coefficient) and were considered significant if zero did not fall within the bootstrapped 95% confidence interval (Hayes, 2009).

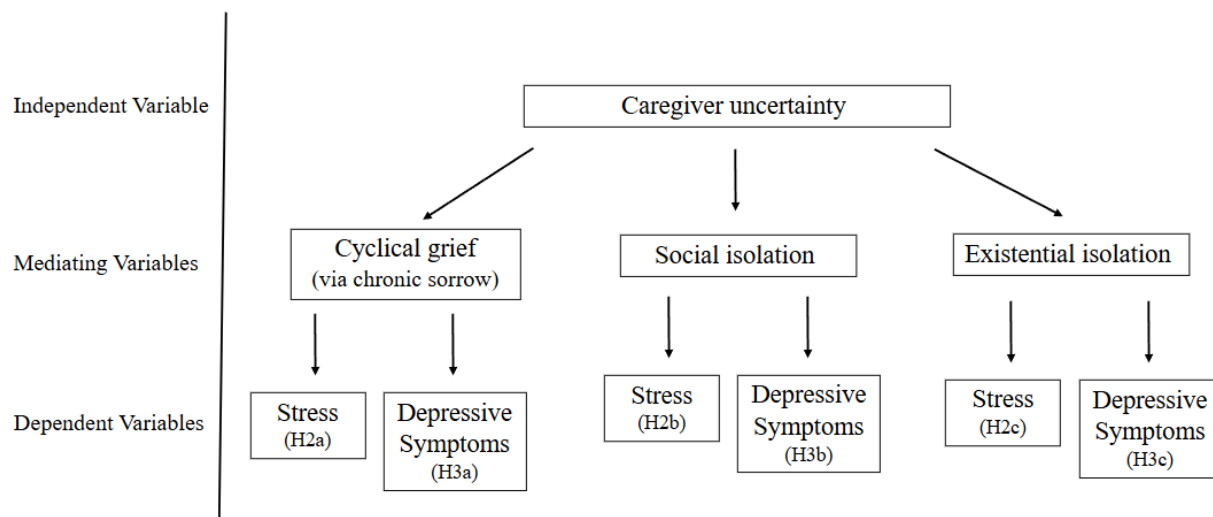


Figure 2: Mediation Analyses and Associated Hypotheses

RESULTS

Preliminary Examination of the Data

Initial checks of the data indicated that there was less than 5% of data missing at the item level (4 data points) and no data missing at the scale level. Additionally, all variables were normally distributed (minimal skewness or kurtosis), and no extraneous outliers were present. An independent samples t-test indicated no significant differences in uncertainty, chronic sorrow, social isolation, existential isolation, and depression scores between male and female caregivers. However, there was a significant difference in stress levels between male and female caregivers ($t(151) = -2.81, p = .006, d = .52; 95\% \text{ CI's } [-.81, -.14]$) with women experiencing greater stress ($M_{\text{stress}} = 2.91, SD_{\text{stress}} = .91$) compared to men ($M_{\text{stress}} = 2.43, SD_{\text{stress}} = .93$; see Table 2).

Main Hypotheses

Hypothesis 1: There Would Be a Significant, Positive Association Between All Variables in the Model.

As seen in Table 2, most study variables were significantly and positively correlated with each other with the exception of social isolation, which was not related to either uncertainty or chronic sorrow. Scatterplots for non-significant associations were reviewed to investigate possible non-linear relationships, but none were evident.

Hypothesis 2a: Chronic Sorrow Will Mediate the Relationship Between Uncertainty and Caregiver Stress.

As seen in Table 3, results of the first mediation analysis (M_1) indicated that there was a significant indirect effect of chronic sorrow on caregiver stress, and a significant direct effect of caregiver uncertainty on caregiver stress, suggesting that chronic sorrow mediates the

	Child Age	Caregiver Age	SES	Caregiver Uncertainty	Chronic Sorrow	Social Isolation+	Existential Isolation	Caregiver Depressive Symptoms	Caregiver Stress
Variable Mean	8.76	38.83	4.82	2.69	2.70	1.08	4.82	1.14	2.81
Variable SD	4.02	7.6	1.73	.74	1.30	.89	2.05	.80	.94
Child Age	-								
Caregiver Age	.44**	-							
SES	.002	.08	-						
Caregiver Uncertainty	.05	.05	-.04	-					
Chronic Sorrow	-.04	.006	.04	.57**	-				
Social Isolation+	.002	.01	-.41**	.03	-.02	-			
Existential Isolation	.06	.01	-.32**	.16*	.17*	.22*	-		
Caregiver Depressive Symptoms	-.05	-.12	-.31**	.31**	.46**	.21*	.45**	-	
Caregiver Stress	-.06	-.03	-.23**	.51**	.65**	.16*	.32**	.68**	-

Table 2. Correlations Between Caregiver and Child Demographics with All Study Variables. Note: ** $p < .001$; * $p < .05$; + Spearman's Rho Correlations were conducted for the relationship between social isolation and all other variables of interest. Nonparametric correlations were not appreciably different from Pearson correlations

relationship between caregiver uncertainty and caregiver stress. These results provide initial support for hypothesis 2a (Figure 3).

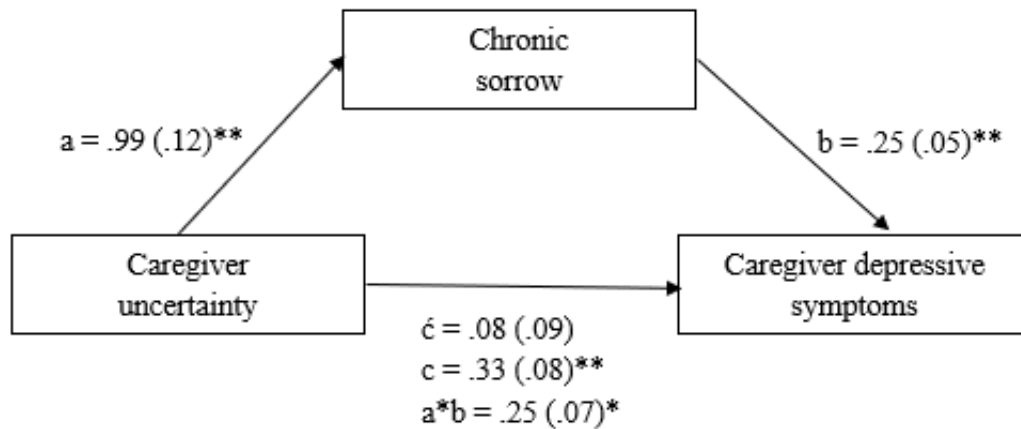


Figure 3. Direct and Indirect Effects of Caregiver Uncertainty on Caregiver Depressive Symptoms as Mediated by Chronic Sorrow. Note: ** = $p < 0.05$; * = LLCI and ULCI do not contain 0. Analyses controlling for SES and child age found no differences in direct or indirect effects.

Hypothesis 2b and 2c: Existential Isolation and Social Isolation Will Mediate the Relationship Between Uncertainty and Caregiver Stress.

As seen in Table 3, results of the second (M_2) and third (M_3) mediation analyses indicate that there was not a significant indirect effect of social isolation or existential isolation on caregiver stress, suggesting that neither mediates the relationship between uncertainty and caregiver stress. These results do not provide support for hypothesis 2b and 2c.

Hypothesis 3a. Chronic Sorrow Will Mediate the Relationship Between Uncertainty and Caregiver Depressive Symptoms.

As seen in Table 4, results of the fourth mediation analysis (M_4) indicated that there was a significant indirect effect of chronic sorrow on caregiver depressive symptoms and a

Paths	Effect	SE	Boot 95% LLCI	Boot 95% ULCI
Chronic Sorrow (M ₁)				
Total Effect (c)	.65	.09	.47	.82
Direct Effect ($\acute{c}_1$)	.26	.09	.08	.45
a ₁	1.0	.12	.77	1.23
b ₁	.39	.05	.28	.49
Indirect Effect (a ₁ *b ₁)	.39	.07	.26	.52
Social Isolation (M ₂)				
Total Effect (c)	.65	.09	.47	.82
Direct Effect ($\acute{c}_2$)	.65	.09	.47	.82
a ₂	.02	.10	-.17	.21
b ₂	.17	.07	.03	.32
Indirect Effect (a ₂ *b ₂)	.003	.02	-.03	.04
Existential Isolation (M ₃)				
Total Effect (c)	.65	.09	.47	.82
Direct Effect ($\acute{c}_3$)	.60	.09	.43	.77
a ₃	.45	.22	.02	.90
b ₃	.11	.03	.05	.18
Indirect Effect (a ₃ *b ₃)	.05	.04	-.003	.13

Table 3. Mediation Analysis with Stress as the Outcome. Notes: LLCI = Lower level confidence intervals; ULCI = Upper level confidence intervals; a₁, a₂, a₃ = regression coefficients of caregiver uncertainty predicting chronic sorrow, social isolation, and existential isolation, respectively; b₁, b₂, b₃ = regression coefficients of chronic sorrow, social isolation, and existential isolation predicting depressive symptoms, respectively; $\acute{c}_1$, $\acute{c}_2$, $\acute{c}_3$ = the total effect of uncertainty on caregiver depressive symptoms controlling for chronic sorrow, social isolation, or existential isolation respectively; c = the direct effect of uncertainty on caregiver depressive symptoms; Additional mediation analyses were conducted for each variable of interest controlling for socioeconomic status and child age, but the addition of either covariate did not change the indirect effect of any variable on stress.

non-significant direct effect of caregiver uncertainty on caregiver depressive symptoms, suggesting that chronic sorrow fully mediates the relationship between caregiver uncertainty and caregiver depressive symptoms. These results provide support for hypothesis 3a (Figure 4)

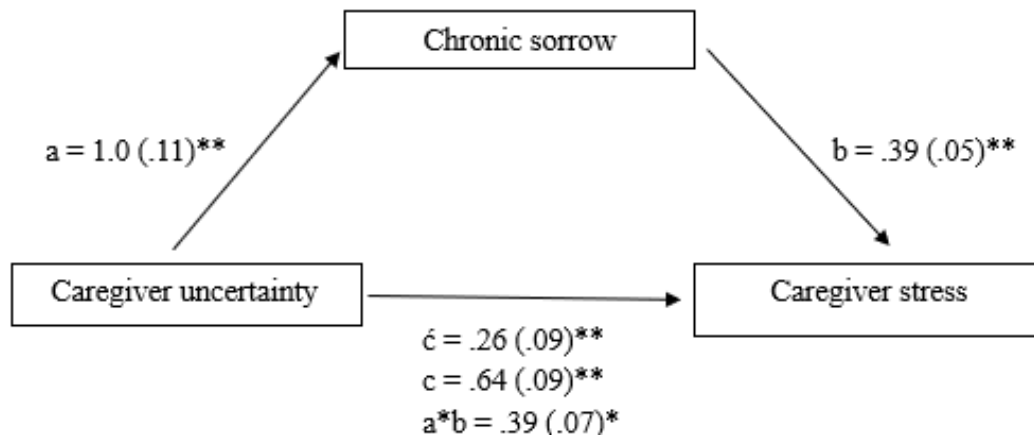


Figure 4. Direct and Indirect Effects of Caregiver Uncertainty on Caregiver Stress as Mediated by Chronic Sorrow. Note: ** = $p < 0.05$; * = LLCI and ULCI do not contain 0; Analyses controlling for SES found no differences in direct or indirect effects.

Hypothesis 3b and 3c: Existential Isolation and Social Isolation Will Mediate the Relationship Between Uncertainty and Depressive Symptoms.

As seen in Table 4, results of mediation analyses five (M₅) and six (M₆) indicate that there was not a significant indirect effect of social isolation or existential isolation on caregiver depressive symptoms, suggesting that neither mediates the relationship between uncertainty and caregiver depressive symptoms. These results do not provide support for hypothesis 3b and 3c.

Paths	Effect	SE	Boot 95% LLCI	Boot 95% ULCI
Chronic Sorrow (M ₄)				
Total Effect (c)	.33	.08	.17	.50
Direct Effect ($\acute{c}_4$)	.08	.09	-.11	.27
a ₄	1.0	.12	.76	1.23
b ₄	.25	.05	.15	.36
Indirect Effect (a ₄ *b ₄)	.25	.07	.12	.38
Social Isolation (M ₅)				
Total Effect (c)	.33	.08	.17	.50
Direct Effect ($\acute{c}_5$)	.33	.08	.17	.49
a ₅	.02	.10	-.17	.21
b ₅	.22	.06	.08	.35
Indirect Effect (a ₅ *b ₅)	.004	.02	-.04	.05
Existential Isolation (M ₆)				
Total Effect (c)	.33	.08	.17	.50
Direct Effect ($\acute{c}_6$)	.26	.08	.11	.41
a ₆	.45	.22	.02	.90
b ₆	.16	.03	.11	.21
Indirect Effect (a ₆ *b ₆)	.07	.04	-.01	.16

Table 4. Mediation Analysis with Depressive Symptoms as the Outcome. Notes: LLCI = Lower level confidence intervals; ULCI = Upper level confidence intervals; a₄, a₅, a₆ = regression coefficients of caregiver uncertainty predicting chronic sorrow, social isolation, and existential isolation, respectively; b₄, b₅, b₆ = regression coefficients of chronic sorrow, social isolation, and existential isolation predicting depressive symptoms, respectively; $\acute{c}_4$, $\acute{c}_5$, $\acute{c}_6$ = the total effect of uncertainty on caregiver depressive symptoms controlling for chronic sorrow, social isolation, or existential isolation respectively; c = the direct effect of uncertainty on caregiver depressive symptoms; Additional mediation analyses were conducted for each variable of interest controlling for socioeconomic status and child age, but the addition of either covariate did not change the indirect effect of any variable on depression.

Multiple Regression Analyses

The relationships between the variables of interest in the present study are novel within this population, prompting the use of post hoc sensitivity analyses to clarify the unique role each variable plays in the model. Specifically, these analyses determine whether the independent variable (uncertainty) and mediators (chronic sorrow, social isolation, and existential isolation) were uniquely related to each dependent variable (stress and depression), while controlling for each other. Caregiver uncertainty, chronic sorrow, social isolation, and existential isolation were entered as the independent variables in the first regression analysis and caregiver depressive symptoms as the dependent variable. As seen in Table 5, results indicated that the independent variables explained 36.3% of the variance in caregiver depressive symptoms, and, interestingly, that uncertainty was not associated with caregiver depressive symptoms. Additionally, chronic sorrow and existential isolation were moderately associated with caregiver depressive symptoms, while social isolation was weakly, but significantly associated with caregiver depressive symptoms.

Variable	Adj R ²	b	SE	β	<i>t</i>	<i>p</i>	VIF
Full Model	.363**						
Caregiver Uncertainty		.04	.09	.04	.45	.65	1.48
Chronic Sorrow		.23	.05	.38	4.85	<.001	1.49
Social Isolation		.16	.06	.17	2.65	.009	1.1
Existential Isolation		.13	.03	.34	5.10	<.001	1.1

Table 5. Multiple Regression with Caregiver Depressive Symptoms as the Criterion Variable.

Notes: ** $p < .001$; $F(4, 151) = 23.07$

In the second mediation analysis, caregiver uncertainty, chronic sorrow, social isolation, and existential isolation were entered as the independent variables, and caregiver stress was entered as the dependent variable. As seen in Table 6, results indicated that the independent

variables explained 50% of the variance in caregiver stress, and that all variables of interest were associated with caregiver stress after controlling for the other variables in the model. Chronic sorrow and existential isolation produced strong effects on caregiver stress after controlling for other independent variables, while social isolation and caregiver uncertainty produced small, but significant, effects on caregiver stress.

Variable	Adj R ²	b	SE	β	<i>t</i>	<i>p</i>	VIF
Full Model	.50**						
Caregiver Uncertainty		.24	.09	.19	2.66	.009	1.48
Chronic Sorrow		.37	.05	.52	7.41	<.001	1.49
Social Isolation		.14	.06	.13	2.26	.03	1.1
Existential Isolation		.08	.03	1.8	2.99	.003	1.09

Table 6. Multiple Regression with Caregiver Stress as the Criterion Variable. Notes: ** $p < .001$; $F(4, 151) = 39.03$

DISCUSSION

The current study tested a novel theoretical model (Figure 1) that delineates the associations between uncertainty, chronic sorrow, social isolation and existential isolation, and their effects on stress and depressive symptoms in caregivers of children with ASD. Uncertainty (Bravo-Benítez et al., 2019), chronic sorrow (Bravo-Benítez et al., 2019; Krishnan et al., 2017), social isolation (Pepperell et al., 2018; Samsell et al., 2021), stress (Boyd, 2002) and depressive symptoms (Pepperell et al., 2018) have each been independently observed in caregivers raising a child with autism, though this is the first study to investigate the associations between all of these variables. Notably, this study was the first to assess existential isolation in this population and found that caregivers experiencing greater existential isolation also reported greater stress and depressive symptoms and offer support for previous studies that have found existential isolation to be related to both stress and depressive symptoms (Helm et al., 2020; Constantino et al., 2019). Additionally, this study was the first to find that caregivers in this population who felt more chronic sorrow also experienced greater stress and depressive symptoms. Previous studies support the presence of chronic sorrow in this population (Olshansky, 1962, Bravo-Benítez et al., 2019), though this is the first study to assess its relationship with caregiver stress and depressive symptoms.

After controlling for other variables in the model using mediation analyses, results indicate that chronic sorrow was the only mediator linking caregiver uncertainty to both stress and depression in the model. Chronic sorrow served as a partial mediator in the relationship between uncertainty and stress, demonstrating support for hypothesis 2a. These findings suggest that the relationship between uncertainty and caregiver stress is partially explained by chronic

sorrow (Bravo-Benítez et al., 2019; Olshansky, 1962), indicating that other factors also contribute to caregiver stress.

Additionally, chronic sorrow served as a full mediator in the relationship between uncertainty and depressive symptoms. This finding provides support for hypothesis 3a, suggesting that the relationship between caregiver uncertainty and depressive symptoms is fully accounted for by chronic sorrow. This finding was further supported in multiple regression analyses as uncertainty was not a significant predictor of depressive symptoms when controlling for the other variables of interest (chronic sorrow, social isolation, and existential isolation). While the present study found a relationship between uncertainty and depressive symptoms at the zero-order level, the null relationship between these variables in the presence of other predictors (particularly chronic sorrow) indicates that other variables mitigate the importance of this relationship. The cyclical nature of chronic sorrow (Olshansky, 1962) and its theorized link to caregiver grief (Bravo-Benítez et al., 2019) could explain its strong relationship to caregiver depressive symptoms.

The current study did not find support for hypothesis 2b or 3b as social isolation did not serve as a mediator between either uncertainty and stress or uncertainty and depressive symptoms. This is likely because social isolation was not found to be related to uncertainty in zero-order correlations in the present study. Social isolation was, however, related to both stress and depressive symptoms in both the correlational analysis and multiple regression analyses. These findings indicate that social isolation is an important factor in understanding stress and depression in this population, which replicates prior work (Pepperell et al., 2018; Samsell et al., 2021), however, social isolation does not appear to contribute to understanding the relationship between either uncertainty and stress or uncertainty and depressive symptoms. These findings

suggest that there are other mediating variables not measured in this study that may add to the relationship between uncertainty and both stress depressive symptoms such as reduced caregiver free time due to caregiving demands (Bravo-Benítez et al., 2019).

The present study did not find support for hypothesis 2c or 3c, signifying that existential isolation did not serve as a mediator between either uncertainty and depressive symptoms or uncertainty and stress. As was the case with social isolation, the present study found existential isolation to have a relationship with both stress and depression in zero-order correlations, and that these relationships were still present even after considering other variables in the multiple regression analyses. These findings suggest that existential isolation explains unique variance in caregiver stress and depressive symptoms but does not explain the relationship between either uncertainty and stress or uncertainty and depressive symptoms. The present work is the first to examine existential isolation among caregivers of children with ASD. Given that existential isolation independently predicts lower mental health even after accounting for other more well-established predictors of mental health, it suggests that existential isolation may be important for future studies assessing caregiver well-being to consider.

The present study highlights the need for adjustments to the original model. A potential alternative model, as seen in Figure 5, suggests that social isolation and existential isolation emerge in parallel with, rather than as outcomes of, uncertainty following the child's diagnosis. Given their lack of mediation in the present study, the updated model also suggests that social and existential isolation will lead directly to the development of stress and depressive symptoms in these caregivers instead of serving as mediating variables. Chronic sorrow, however, continues to function as a mediating variable in the relationship between uncertainty and both stress and depressive symptoms as results supported its role as a mediator in that relationship.

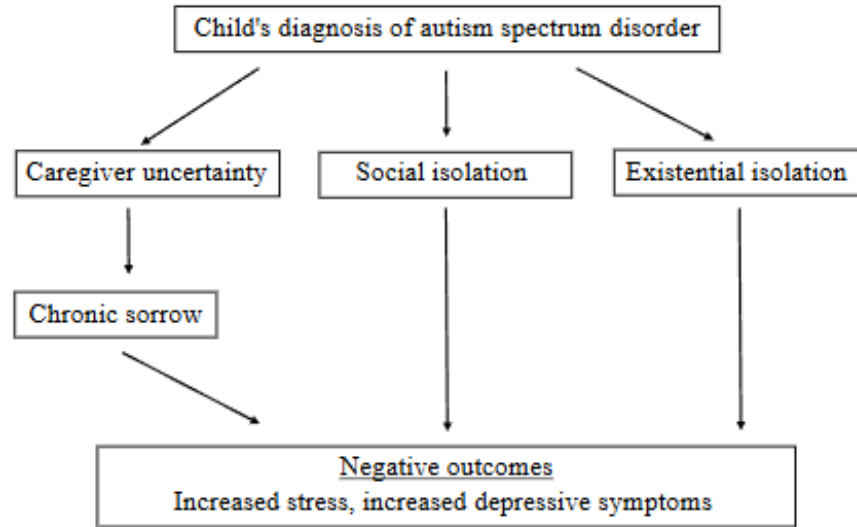


Figure 5. Adapted Model Based on Study Results

Limitations and Future Directions

While this study offers novel insights, it is important to address its limitations. Future studies should include a measure of ASD symptom severity so that it can serve as a covariate in analyzing the relationships within the present model. This may have an impact on caregiver stress and depressive levels as different symptom severities may require different demands from caregivers. Moreover, the cross-sectional nature of this study measures the main variables of interest at one point in time. It is possible that certain variables can have a reverse effect on others that the current study did not intend to measure. Specifically, depression can lead individuals to self-isolate and experience feelings of worthlessness. These experiences may, in turn, worsen uncertainty, chronic sorrow, social isolation and existential isolation in this population. This is particularly important because the mediation models utilized in this study assume causal relationships between the variables of interest, and the cross-sectional data cannot

inform causal pathways. Future studies should employ a longitudinal study design to assess directionality which may more accurately capture the relationship between the model variables.

The use of the Social Isolation Index (Steptoe et al., 2013) may also pose additional limitations. The Social Isolation Index was initially adapted to measure social isolation in older adults, an age group that was not our target population. It is possible that the developmental period our sample represented may not be susceptible to social isolation for two reasons. First, the items in the Social Isolation Index may have been better fit for older adults compared to caregivers currently raising children. Importantly, caregivers in our sample were still in communication with their children (per inclusionary criteria), and a number were married ($n = 112$). Thus, caregivers in our sample presumably selected a score of “0” for the item pertaining to communication with children, while those that were married presumably selected a “0” for the item pertaining to communication with a spouse. This may have positively skewed the level of isolation caregivers felt as meeting these criteria would reduce their summed isolation score, inadvertently leading to systematic measurement error. Secondly, children in our sample had to have received a diagnosis of ASD within the last five years. This criterion, while important for capturing some variables, may not have allowed enough time for the negative impact of social isolation to manifest in this sample. Caregivers who are still adjusting to raising a child with ASD may not yet feel isolated as they are still learning how best to manage their social relationships alongside their child’s needs. However, social isolation predicted depression and stress in zero-order correlations and in the multiple regression analyses. Thus, even if the average social isolation score of the present sample was lower than the broader caregiver population, those with greater isolation still robustly reported worse mental health. Future studies should

utilize a measure of social isolation adapted specifically to caregivers, or those in a younger age group.

Conclusion

The current study indicates that chronic sorrow is the most salient predictor in the relationship between uncertainty and both caregiver stress and depressive symptoms, providing initial support for its inclusion in the model. Social isolation and existential isolation did not play a key role in understanding the relationship between uncertainty, stress and depression as initially hypothesized. However, in multiple regression analyses, all constructs of interest (uncertainty, chronic sorrow, existential isolation, and social isolation) were independent predictors of caregiver stress, and all but uncertainty were independent predictors of caregiver depression. These results highlight the importance of these experiences in caregiver mental health. Replication of the current study and further testing of the proposed model will help establish the constructs involved in the development of stress and depressive symptoms in this population and help devise therapeutic approaches to assist caregivers in this population.

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APPENDICES

APPENDIX A

EXCLUSIONARY CRITERIA

1. Do you reside in the United States?
 - a. Yes
 - b. No
2. Does your child have a diagnosis of autism spectrum disorder?
 - a. Yes
 - b. No
3. How many years ago did your child receive their diagnosis?
 - a. Within the last year
 - b. 1-2 years
 - c. 2-3 years
 - d. 3-4 years
 - e. 4-5 years
 - f. 6+ years

APPENDIX B

CHILD DEMOGRAPHICS

1. What is your child's age?
 - a. [text response]
2. What is your child's gender?
 - a. Male
 - b. Female
 - c. Non-binary/gender non-conforming
 - d. Transgender
 - e. Other: _____
 - f. Prefer not to say
3. What is your child's race/ethnicity (select all that apply)?
 - a. Asian, Asian American, Pacific Islander
 - b. Black / African American
 - c. Native American, Alaskan Native
 - d. White
 - e. Hispanic or Latino
 - f. Other (please specify)
 - i. [text response]
 - g. Prefer not to say/unsure
4. Does your child have a chronic physical illness in addition to autism (e.g. cancer, diabetes, spina bifida, etc.)?
 - a. Yes
 - b. No
5. Who provided your child with their autism diagnosis?
 - a. Clinical psychologist/licensed psychologist
 - b. Medical doctor/pediatrician
 - c. Neurologist/neuropsychologist
 - d. School counselor
 - e. Board certified behavior analyst
 - f. Other (please specify)
 - i. [text response]
 - g. Unsure

APPENDIX C

CAREGIVER DEMOGRAPHICS

1. What is your age?
 - a. [text response]
2. What is your gender?
 - a. Male
 - b. Female
 - c. Non-binary/gender non-conforming
 - d. Transgender
 - e. Other (please specify)
 - f. Prefer not to say
3. What is your race/ethnicity (select all that apply)?
 - a. Asian, Asian American, Pacific Islander
 - b. Black / African American
 - c. Native American, Alaskan Native
 - d. White
 - e. Hispanic or Latino
 - f. Other (please specify)
 - i. [text response]
 - g. Prefer not to say/unsure
4. Do you, the caregiver, have an intellectual or developmental disability (e.g. autism, fragile x syndrome)
 - a. Yes
 - b. No
5. What is your marital status?
 - a. Married
 - b. Divorced
 - c. Separated
 - d. Partnered
 - e. Widowed
 - f. Single
 - g. Prefer not to say
 - h. Other (please specify)
 - i. [text response]
6. What is your relationship to the child?
 - a. Biological mother
 - b. Biological father
 - c. Adoptive mother
 - d. Adoptive father
 - e. Grandmother
 - f. Grandfather
 - g. Aunt
 - h. Uncle

- i. Foster parent
 - j. Other (please specify)
 - i. [text response]
 - k. Prefer not to say
7. What is the zip code of your current residence?
- a. [text response]
8. How many hours a day do you spend providing direct support to your child with autism?
- a. [text response]
9. Are there other children in your home that receive direct care from you? NOTE: This does NOT include the child for whom you are filling this survey out.
- a. Yes
 - i. If yes...
 - 1. Please include the following about the other children in your home
 - a. Child 1
 - i. Age
 - ii. Does the child have a diagnosis of autism
 - 1. Yes
 - 2. No
 - b. Child 2
 - i. Age
 - ii. Does the child have a diagnosis of autism
 - 1. Yes
 - 2. No
 - c. Child 3
 - i. Age
 - ii. Does the child have a diagnosis of autism
 - 1. Yes
 - 2. No
 - d. Child 4
 - i. Age
 - ii. Does the child have a diagnosis of autism
 - 1. Yes
 - 2. No
 - e. Child 5
 - i. Age
 - ii. Does the child have a diagnosis of autism
 - 1. Yes
 - 2. No
 - f. Child 6
 - i. Age
 - ii. Does the child have a diagnosis of autism
 - 1. Yes

2. No

b. No

10. At the top of the ladder are the people who are the best off, those who have the most money, most education, and best jobs. At the bottom are the people who are the worst off, those who have the least money, least education, worst jobs, or no job. Please select the rung that best represents where you think you stand on the ladder.



- a. 1
- b. 2
- c. 3
- d. 4
- e. 5
- f. 6
- g. 7
- h. 8
- i. 9
- j. 10

APPENDIX D

PARENTS' UNCERTAINTY REGARDING THEIR CHILD WITH ACUTE ILLNESS SCALE

Ueki, Shingo & Komai, Kazuyo & Ohashi, Kazutomo. (2017). Development of a Scale to Screen Parents with Uncertainty Regarding Their Child with Acute Illness. *Open Journal of Nursing*. 07. 1246-1257. 10.4236/ojn.2017.711090.

	1 – Strongly Disagree	2 – Disagree	3 – Neither Agree nor Disagree	4 – Agree	5 – Strongly Agree
I cannot predict the course of my child's mental health condition	1	2	3	4	5
I cannot imagine how I will manage the care of my child.	1	2	3	4	5
I am not sure how I can make my child comfortable	1	2	3	4	5
I cannot determine the seriousness of my child's mental health condition	1	2	3	4	5
I am unsure what is normal for my child.	1	2	3	4	5
I am unsure if my child's mental health condition is getting better or worse	1	2	3	4	5
It is unclear if my child's behavior is because of some symptoms	1	2	3	4	5
It is unclear what is happening to my child	1	2	3	4	5
It is difficult to understand what my child wants	1	2	3	4	5
I don't know where to look to determine the state of my child's mental health condition	1	2	3	4	5
I am not sure how much attention I should pay to my child	1	2	3	4	5
I don't know how much I should restrict my child's behavior	1	2	3	4	5
I don't know which foods and drinks I should give to my child	1	2	3	4	5
It is not clear when I should call for help	1	2	3	4	5
I am not sure whether my care for my child is correct	1	2	3	4	5
I don't know why my child developed a mental health condition.	1	2	3	4	5

I don't know when my child developed a mental health condition.	1	2	3	4	5
I think of different reasons why my child developed a mental health condition.	1	2	3	4	5

APPENDIX E

KENDALL'S CHRONIC SORROW INSTRUMENT

Kendall, L. C. (2005). *The experience of living with ongoing loss: Testing the kendall chronic sorrow instrument* (Order No. 3196497). Available from ProQuest One Academic. (305349131). Retrieved from <https://www.proquest.com/dissertations-theses/experience-living-with-ongoing-loss-testing/docview/305349131/se-2>

	0 – Almost Never	1 – Infrequently	2 – Usually Not	3 – Not Sure	4 – Sometimes	5 – Frequently	6 – Almost Always
I think about the diagnosis as if it just happened.	0	1	2	3	4	5	6
I feel saddened when I think of the diagnosis.	0	1	2	3	4	5	6
I feel just as sad when I think of the diagnosis as I did when the diagnosis first happened	0	1	2	3	4	5	6
I feel like crying when something reminds me of the diagnosis.	0	1	2	3	4	5	6
I feel full of sorrow.	0	1	2	3	4	5	6
I feel sadness when I'm reminded of the diagnosis.	0	1	2	3	4	5	6
I feel saddened by things that other people see as unimportant or minor.	0	1	2	3	4	5	6
I feel full of sorrow when I think about what might or could have been if the diagnosis had not happened.	0	1	2	3	4	5	6
I feel that the sadness related to	0	1	2	3	4	5	6

the diagnosis comes and goes							
I feel that I have to give up things in my life because of the diagnosis	0	1	2	3	4	5	6
I feel that I have control over my life situation. (R)	0	1	2	3	4	5	6
I feel my life is not the same as I had hoped or dreamed it would be because of the diagnosis.	0	1	2	3	4	5	6
I think about what my life might have or could have been when I am reminded of the diagnosis.	0	1	2	3	4	5	6
I feel alone during times that I feel sadness related to the diagnosis	0	1	2	3	4	5	6
I feel that I have enough energy to deal with my life. (R)	0	1	2	3	4	5	6
The changes in my life because of diagnosis are unfair.	0	1	2	3	4	5	6
I believe that life is unfair.	0	1	2	3	4	5	6
I feel older than my age because of the diagnosis.	0	1	2	3	4	5	6

APPENDIX F

SOCIAL ISOLATION INDEX

Steptoe A, Shankar A, Demakakos P, Wardle J. Social isolation, loneliness, and all-cause mortality in older men and women. *Proceedings of the National Academy of Sciences*. 2013;110(15):5797–5801.

1. Are you married or cohabitating with a partner?

Yes	No
-----	----

2. How often do you have contact (face-to-face, telephone, written, or electronic) with your children?

1 – Less than monthly	2 – Monthly	3 – Two or three times per month	4 – About once a week	5 – More than once a week	6 – Not applicable
-----------------------	-------------	----------------------------------	-----------------------	---------------------------	--------------------

3. How often do you have contact with your other immediate family members?

1 – Less than monthly	2 – Monthly	3 – Two or three times per month	4 – About once a week	5 – More than once a week	6 – Not applicable
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4. How often do you have contact with friends?

1 – Less than monthly	2 – Monthly	3 – Two or three times per month	4 – About once a week	5 – More than once a week	6 – Not applicable
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5. Do you participate in any organizations, religious groups, clubs, gyms, or committees?

Yes	No
-----	----

APPENDIX G

EXISTENTIAL ISOLATION SCALE

Pinel, E. C., Long, A. E., Murdoch, E. Q., & Helm, P. (2017). A prisoner of one's own mind: Identifying and understanding existential isolation. *Personality and Individual Differences*, 105, 54–63. <https://doi.org/10.1016/j.paid.2016.09.024>

Please rate the extent to which you agree or disagree with each of the following statements:

1. I usually feel like people share my outlook on life (R)

0 – Strongly disagree	1	2	3	4	5	6	7	8	9 – Strongly agree
-----------------------	---	---	---	---	---	---	---	---	--------------------

2. I often have the same reactions to things that other people around me do (R)

0 – Strongly disagree	1	2	3	4	5	6	7	8	9 – Strongly agree
-----------------------	---	---	---	---	---	---	---	---	--------------------

3. People around me tend to react to things in our environment the same way I do (R)

0 – Strongly disagree	1	2	3	4	5	6	7	8	9 – Strongly agree
-----------------------	---	---	---	---	---	---	---	---	--------------------

4. People **do not** often share my perspective

0 – Strongly disagree	1	2	3	4	5	6	7	8	9 – Strongly agree
-----------------------	---	---	---	---	---	---	---	---	--------------------

5. Other people usually **do not** understand my experiences

0 – Strongly disagree	1	2	3	4	5	6	7	8	9 – Strongly agree
-----------------------	---	---	---	---	---	---	---	---	--------------------

6. People often have the same “take” or perspective on things that I do (R)

0 – Strongly disagree	1	2	3	4	5	6	7	8	9 – Strongly agree
-----------------------	---	---	---	---	---	---	---	---	--------------------

APPENDIX H

PATIENT HEALTH QUESTIONNAIRE - 8

Kroenke K, Strine TW, Spritzer RL, Williams JB, Berry JT, Mokdad AH. The PHQ-8 as a measure of current depression in the general population. *J Affect Disord.* 2009; 114(1-3):163-73

Over the last 2 weeks, how often have you been bothered by any of the following problems?

	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself – or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed. Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual.	0	1	2	3

APPENDIX I

THE KINGSTON CAREGIVER STRESS SCALE

Hopkins R, & Kilik L. (2016) "The Kingston Caregiver Stress Scale (KCSS)" (KCSS Descriptive Paper) <http://www.kingstonscales.org/caregiver-stress-scale.html>

Some people report feelings of stress surrounding certain aspects of care giving. To what extent, if any, do these apply to you in your role of care giving to your spouse or relative? Using a 5 point rating scale, where 1 equals no stress and 5 equals extreme stress, indicate the extent of the stress or frustration you feel surrounding the following issues.

1 = Feeling NO stress (coping fine, no problems); 2 = Some stress; 3 = Moderate stress; 4 = A lot of stress; 5 = Extreme stress (Feeling at "end of rope", health at risk)

Care Giving Issues

To what extent...

1. Are you having feelings of being overwhelmed, over worked, and/or over burdened?

1	2	3	4	5
---	---	---	---	---

2. Has there been a change in your relationship with your spouse/relative?

1	2	3	4	5
---	---	---	---	---

3. Have you noticed any changes in your social life?

1	2	3	4	5
---	---	---	---	---

4. Are you having any conflicts with your previous daily commitments (work/volunteering?)

1	2	3	4	5
---	---	---	---	---

5. Do you have feelings of being confined or trapped by the responsibilities or demands of care giving?

1	2	3	4	5
---	---	---	---	---

6. Do you ever have feelings related to a lack of confidence in your ability to provide care?

1	2	3	4	5
---	---	---	---	---

7. Do you have concerns regarding the future care needs of your spouse/relative

1	2	3	4	5
---	---	---	---	---

Family Issues

To what extent...

8. Are you having any conflicts within your family over care decisions?

1	2	3	4	5
---	---	---	---	---

9. Are you having any conflicts within your family over the amount of support you are receiving in providing care?

1	2	3	4	5
---	---	---	---	---

Financial Issues

To what extent...

10. Are you having financial difficulties associated with care giving?

1	2	3	4	5
---	---	---	---	---

APPENDIX J

CONCLUDING ITEMS

1. Where did you hear about/receive this survey
 - a. Reddit
 - b. Facebook
 - c. Clinic email
 - d. Friend
 - e. Family member
 - f. CloudResearch Connect
 - g. Other (please specify)
 - i. Text entry
2. If you know anyone else who would be interested in completing this survey, please direct them to: <https://www.montana.edu/caalmlab/CECA.html>
3. We sincerely thank you for taking the time to complete this survey. Your thoughtful responses will help researchers to understand more about potential sources of parental burden in raising a child with autism. This study in particular aims at understanding potential increases in parent uncertainty, grief, and social isolation following their child's diagnosis with autism spectrum disorder. Findings from this study will be used to further understand these experiences and can potentially inform the development of effective parent education programs in the future. Knowing this, is there anything else you would like to add regarding your experiences in parenting a child with autism spectrum disorder?
 - a. [text entry]

APPENDIX K

PARTICIPANT RESOURCES AND CLOSING STATEMENT

If you are interested in learning more, getting connected, or receiving support, here is a curated list of trusted resources designed to offer guidance, community, and additional learning opportunities for individuals with autism, their families, and caregivers.

1) Educational Resources

- Autism Self Advocacy Network (ASAN): The Autism Self Advocacy Network offers a range of educational resources including books and toolkits on a variety of topics, as well as an overview of what autism is. These resources can be found here: <https://autisticadvocacy.org/>
- Interactive Autism Network (IAN): IAN provides online resources, including research updates and educational guides for both caregivers and individuals on the spectrum. Visit <https://www.iancommunity.org> for more details.

2) Community and Support Groups

- Autism Society of America: The Autism Society provides local chapter support groups across the U.S., along with online discussion boards and resources. Find your local chapter at: <https://www.autism-society.org>
- Social media: Platforms like Facebook groups and Reddit threads provide informal support for parents and caregivers by fostering connections with others who are also raising children with autism.

3) Counseling and Mental Health Support

- Autism Response Team (ART): Autism Speaks provides the Autism Response Team, a helpline that offers support and information for individuals and families affected by autism. Reach out via their helpline at: <https://www.autismspeaks.org/autism-response-team>.
- SAMHSA National Helpline: The Substance Abuse and Mental Health Services Administration provides a 24/7 helpline at 1-800-662-HELP (4357) for mental health support, including assistance tailored for those with autism and their caregivers.

We hope these resources are useful to you and provide additional tools and connections beyond this study.

Thank you for your participation in this survey! If you experienced any discomfort answering these questions, contact us at CAALMMSU@gmail.com or 406-994-5218 (or brandon.scott2@montana.edu).

If you have questions regarding rights of human subjects, you can contact the Chair of Montana State University Institutional Review Board, Mark Quinn at 406-994-4707 or mquinn@montana.edu. If you experienced any distress while answering any of these questions and feel you would like support, you can also contact the National Alliance on Mental Health at 1-800-950-6264 or the Substance Abuse and Mental Health Services Administration at 1-800-662-4357.

APPENDIX L

RECRUITMENT FLYER

ARE YOU CARING FOR A CHILD WITH AUTISM?

We want to hear from you!

WHAT WILL YOU DO

You will be asked to answer questionnaires about your thoughts, feelings, and experiences in raising a child with autism.

The study should take roughly **15 minutes** to complete.

REQUIREMENTS

- You, the caregiver, must not have a diagnosis of an intellectual or developmental disability
- Your child must have a current diagnosis of autism
- The diagnosis must have been obtained within the last 5 years
- The diagnosis must have been obtained from a licensed professional
- Your child must not have any other chronic medical diagnoses (e.g. diabetes, cancer, spina bifida, etc.)

PAYMENT

Participants can choose to be entered for a chance to win one of 20 \$25 Amazon gift cards



IRB#: 2024-1819



Scan me!



APPENDIX M

RECRUITMENT PHONE SCRIPT FOR CLINIC CONTACT

“Hi [Clinic Name], my name is Hannah Lavoie, and I'm calling from Montana State University. We're conducting a study to understand parent's experiences raising a child with autism, and I was wondering if your clinic would be able to distribute a survey to the families you work with.”

If they want to know more:

“I'd be happy to tell you more! We are looking at understanding parent emotional experiences throughout their child's life as well as parent social relationships. This study has been approved by Montana State University's Institutional Review Board and I would be happy to provide the protocol number if you would like. Parents who are interested in participating will fill out a series of surveys completely online. The surveys can be accessed via QR code or through a direct link and will take parents roughly 45 minutes to complete. All parent responses are completely anonymous and are stored on a secure server. No questions will ask for personally identifiable information. Parents can choose to provide their email address to be entered into a gift card drawing, though this is optional, and emails will be kept separate from their survey response. Parents who choose to share their email will be entered for a chance to win one of 20 \$25 Amazon gift cards. If this sounds like something you'd be interest in passing on to your parents, I would be happy to send our flyer and link your way for you to take a look at it before making any decisions.”