EXPLORING FAMILY RESILIENCE AND CONNECTEDNESS DURING A PANDEMIC IN FAMILIES RAISING A CHILD WITH A NEURODEVELOPMENTAL DISORDER

A DISSERTATION IN
Clinical Psychology

Presented to the Faculty of the University
of Missouri Kansas City in partial fulfillment of
the requirements for the degree

DOCTOR OF PHILOSOPHY

by

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2023

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ABSTRACT

Families have been significantly affected by coronavirus disease (COVID-19), and those raising a child with a Neurodevelopmental Disorder (NDD) may be particularly vulnerable to negative consequences from the health catastrophe. Family resilience is a contributing factor to a family's strength in time of hardship and refers to the family's "ability, as a functional system, to withstand and rebound from adversity" (Walsh, 2003, page 1). Additionally, a family's connectedness (e.g., closeness, support, warmth, responsiveness; Manzi & Brambilla, 2014) can help bolster family resilience (Garner & Yogman, 2021). This study sought to first identify how the pandemic has affected families of children with an NDD compared to their neurotypical peers. Second, we wanted to understand whether differences in family resilience and ratings of connectedness existed between the two groups. Third, we analyzed whether family resilience and connectedness were associated with pandemic impact. Finally, we wanted to test whether the relationship between family resilience, connectedness, and pandemic impact was moderated (e.g., strengthened, diminished, or negated) by whether the family had a child with an NDD diagnosis. Caregivers completed questionnaires of family demographics, pandemic impact, and family resilience. Regarding differences in how the pandemic impacted families, our

findings did not suggest that a significant difference existed in how the pandemic impacted (cumulative, indirect, and direct) either group. Next, we analyzed if there was a difference in ratings of overall family resilience between groups, but there was no significant difference in scores. Similarly, there was no significant relationship between family resilience and cumulative pandemic impact. However, there was a moderate, negative correlation between family resilience and indirect pandemic impact, and similar results were found regarding connectedness. Finally, group membership did not moderate the relationship between family resilience and pandemic impact. Implications for how mental health providers can foster and reinforce resilience of all families will be discussed.

APPROVAL PAGE

The faculty listed below, appointed by the Dean of the School of Education, Social Work, and Psychological Sciences, have examined a dissertation titled "Exploring Family Resilience and Connectedness During a Pandemic in Families Raising a Child with a Neurodevelopmental Disorder" presented by Jennifer Olivia Collins, candidate for the Doctor of Philosophy degree, and certify that it is worthy of acceptance.

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ACKNOWLEDGMENTS

I would like to express my deepest gratitude to all those who have contributed to this moment of my academic journey.

First and foremost, I am grateful to my supervisor Dr. Erin Hambrick, for her guidance, support, and encouragement. Her valuable feedback and insights have helped me to improve my work as a clinician and researcher. She has modeled how to create and nurture authentic and equitable community relationships, the importance of work/life-balance, and how to lead effectively from within. Dr. Hambrick's mentorship has equipped me to be a better psychologist as I mentor and serve others.

I would also like to extend my sincere appreciation to the members of my dissertation committee, Drs. Kymberly Bennett, Johanna Nilsson, Darren Olsen, and Joah Williams for their time, expertise, and wisdom. Their feedback and suggestions have greatly enhanced the quality of my work and have helped me carry on with humble confidence. This committee was intentionally formed because I value their expertise and each one has had an indelible impact on my growth as a learner, researcher, and clinician.

I would like to express my gratitude to Dr. Leni Swails and the faculty at Center for Child Health and Development at University of Kansas Medical Center for encouraging me to explore my clinical curiosity out of which this project was formed. Their generosity for funding participant remuneration and conference expenses is greatly appreciated.

Finally, I would like to thank the families who took part in my research. Without their vulnerability to share how their family has been impacted by the COVID-19 pandemic, this study would not have been possible.

DEDICATION

My family has been a constant source of love, encouragement, and motivation for me as I chased after what lights my soul on fire. Thank you to my dad, mom, and brother who have spent countless hours with my kids embarking on many adventures and supporting them as they explored many interests. Corben and Nevien, you are my greatest joy. You have cheered me on and been alongside me from the deepest depths to the highest highs of this journey, I love you. In memory of my grandma who set me on this path by encouraging me to “take just one class and see what happens.” She celebrated with me as I was accepted into graduate school and now guides me from my heart as I often find myself asking “what would she advise me to do?” My family’s unwavering support has been the driving force behind my success. WE did it!

CHAPTER 1

INTRODUCTION

Catastrophes, such as the coronavirus disease (COVID-19) pandemic, can significantly affect families in multiple ways. One group of families that may be particularly vulnerable to negative impacts of catastrophes are families who are raising a child with a neurodevelopmental diagnosis. Families caring for children with a neurodevelopmental disorder, henceforth NDD, (e.g., Autism Spectrum Disorder [ASD], intellectual disability [ID], Attention Deficit Hyperactivity Disorder [ADHD]) may face unique difficulties in times of catastrophe given their child's increased need for health, education, social, and specialized services. Despite the potential challenges, one factor that can contribute to a family's strength in times of hardship is family resilience.

Family resilience has been shown to play a part in reducing, and perhaps even preventing, mental and psychological distress in the face of potential stressors (Fairthorne et al., 2016). Family resilience may be particularly stress-buffering in families of children with an NDD and/or disruptive behaviors, given that many families report that their child's diagnosis has been an opportunity for their family to nurture virtues such as humility, patience, compassion, acceptance, and respect for others (Bayat, 2007). Family resilience relates to a broad array of human functioning (e.g., individual, family, community; Maurović, Liebenberg, & Ferić, 2020), and addresses the often-pondered question of *why do some families adapt and even flourish despite adversity and distress, while others struggle?* Family resilience has been defined as the family's "ability, as a functional system, to withstand and rebound from adversity" (Walsh, 2003, p. 1). Family resilience can also be recognized as the family's capacity "to respond positively to an adverse situation and emerge from the situation

feeling strengthened, more resourceful, and more confident than its prior state" (Simon et al., 2005, p. 427). The COVID-19 pandemic has presented a unique opportunity to explore how families, specifically families of children with preexisting vulnerabilities (e.g., ASD, ADHD, ID), are coping given the enduring and extensive impact of this health-related catastrophe.

The COVID-19 pandemic has had a global, transboundary impact, and has affected all aspects of family life and bringing with it fear, loss, and disruption. The pandemic has been a novel experience and one that does not neatly fit into disaster taxonomy (Ugarte, 2020). Classification of perilous events matters, because it stipulates the aid that is made available and the scope of government response, as well as our understanding of how various types of events affect health. There are three categories of events according to disaster literature (Quarantelli, 2000; Ugarte, 2020): emergencies (e.g., Orlando nightclub shooting, Florida International University pedestrian bridge collapse), disasters (e.g., 2011 Joplin tornado), and catastrophes (e.g., Hurricane Katrina). Though these descriptors are often used interchangeably in media and colloquially, there is extensive discourse within disaster research regarding distinction among the classifications. The Social Science Research Counsel (Ugarte, 2020) offers a brief but succinct differentiation between the three phenomena. Emergencies are managed at the local level. These incidents rely on preexisting plans designed to help a limited amount of people and a smaller scope of impact. Events that have a more substantial effect on the level of need and require a more complex network of aid are classified as disasters. And lastly, events warranting a catastrophe classification are ones that the impact of the event is so widespread, both in magnitude and geography, and the needs of people and communities are so extensive and overwhelming, that they require assistance from both regional and international partners. Catastrophes, while having an

enormous impact on those affected, generally are not long lasting. Considering the ubiquitous nature of the global pandemic there is a call among disaster researchers to consider a reevaluation and refinement of the catastrophe language given the enduring upsets to health and wellbeing, economics, health, and governance systems (Ugarte, 2020). Specifics of policy reform in this arena are beyond the scope of this study, but rather we seek to do our due diligence in contributing to the dialogue and understanding of how the pandemic has affected families and to utilize language consistent with experts in the field of disaster research. Thus, we will offer our perspective through the lens of catastrophe. At the time of this writing, the Centers for Disease Control and Prevention (Centers for Disease Control and Prevention, 2023) reports more than 1.1 millions deaths due to COVID-19 in the United States alone, with millions more people having been infected and affected by the virus. For many, COVID-19 dominated every domain of life and in some cases devastatingly exacerbated pre-existing concerns (e.g., poverty, food and shelter insecurities, inequitable health care, education disparities).

Classification of the disaster type is important and so is the differentiation in the ways the pandemic has impacted families. We found it helpful to not only consider the overall effects of the pandemic as a sole construct, but to also look more closely at the impact of the pandemic in the context of how families were affected. Thus, we operationalized the consequences of the pandemic as either direct or indirect. We defined direct impacts as something unavoidable that occurred due to the pandemic (e.g., being laid off from employment, increase in family responsibility), and indirect impacts can be defined as disturbances that were secondary consequences of the direct impacts, such as relational conflict, distress, and disruptive behaviors from the child. As we move forward into recovery

from the pandemic, it is possible that the way families were impacted may have a bearing on their how well they can recover.

Families with children have been among the largest groups of people significantly impacted by the pandemic (Feinberg et al., 2021). Many public and private schools in the United States transitioned from in-person attendance to varying degrees of remote learning platforms with little time to prepare and limited guidance and resources. This shift resulted in more than 124,000 schools closing which affected more than 55 million students (Chen, Byrne, & Vélez, 2021). A recent survey examining the effects of the pandemic on families in a large urban school district in the Midwest area of the United States found that school closures resulted in a reported 37% increase in behavioral challenges, a 57% increase in emotional distress among children, and a 74% increase in stress among caregivers (The Transition Academy, 2020).

In addition to school and childcare, families often rely on schedules and routines to improve family stability (de Goede et al., 2016) and make their day-to-day lives run smoothly. Reliance on schedules and routines is especially true for families of children with an NDD (Shorey et al. 2021). For example, many parent training programs aimed at managing disruptive behaviors (e.g., Parent Child Interaction Therapy, RUBI, and Helping the Noncompliant Child) encourage families to develop and implement a routine to help their child transition throughout their day and to reduce problematic behaviors. Therapeutic services such as speech, occupational therapy, and behavioral support services, which are often accessed within schools and clinics, scrambled to navigate how they could help their students and patients from a distance. Moreover, families of children with disabilities may have been especially susceptible to the negative outcomes brought about by the pandemic

including loneliness, increased anxiety, emotion regulation problems, and frustration (Kawabe et al., 2020). The disruption of schedules/routines, fears of infection, masking requirements, relational conflict, as well as availability and access to therapeutic services during the pandemic likely added to, or intensified stressors, in families that may already be prone to feel overwhelmed. Adding to this was a digital divide, or the gap in access and availability of technological resources, which often disconnected families from medical and behavioral health services, perhaps increasing feelings of isolation and making continuity of care a barrier to treatment progress. All of these events resulted in cumulative pandemic-related stressors that likely had a profound impact on families of children with an NDD.

The disruption to usual external systems of routine/support, prompted by the pandemic, likely pressed families to rely on one another and draw upon resources from within their family system for support. Research shows that relationships, specifically ones that are safe, stable, and nurturing, are protective and can defend against the effects of stressors and adversity (Centers for Disease Control and Prevention, 2013). These close relationships also help bolster resilience (Garner & Yogman, 2021). The family connection is an important social relationship (Grevenstein et al., 2019) and is central in the development of its members' physical, emotional, social, behavioral, and intellectual abilities (Turner et al., 2017). Connectedness is a factor that contributes to the makeup of family resilience and refers to the closeness, support, warmth, or responsiveness that a family shares (Manzi &Brambilla, 2014). Children who report feeling connected at home and school (e.g., sense of caring, support, belonging) are less likely to experience adverse health related outcomes linked to sexual health, substance use, violence, or mental health (Steiner et al., 2019). Data from this same study also found that adults who recalled feeling a strong sense of connection

when they were young were up to 66% less likely to struggle with mental health issues into adulthood. Overall, higher family resilience is associated with decreased psychological distress. In a study measuring psychological stress (e.g., depression, anxiety, somatic concerns, reduced quality of life; Furnham & Telfor, 2012) in mothers raising children with an NDD, family resilience was a significant moderator between stress and severity of child diagnosis (Suzuki et al., 2018).

There is considerable evidence to suggest that families raising children with an NDD view their experience from a strengths-based perspective (Bayat, 2007) and their child's diagnosis is not the primary crisis-causing stressor in their lives (LeBuffe, Hatchimonji & Elias, 2019). A study of families raising a child with ASD found that though these families had high stress levels to begin with, those that reported greater family resilience had overall lower levels of stress (Plumb, 2011). Given the importance of connectedness and the global stressor of the pandemic, it is imperative to better understand how these factors impact families who are raising a child/ren with an NDD and address this gap in the literature.

Purpose

The purpose of this study was to explore family resilience and the impact of the COVID-19 pandemic on families of children with an NDD compared to families without such diagnoses. The primary goal of this study was to grow in our understanding of the impact of the pandemic and how it affected families of children with an NDD compared to their neurotypical peer families. A second goal of this study was to explore if there were any distinct differences in family resilience and ratings of connectedness between families raising a child with an NDD and those who are not. Thirdly, we were interested in understanding whether family resilience and connectedness are associated with ratings of pandemic impact.

Fourth, we were interested in whether the relationship between family resilience, and also connectedness, and pandemic impact is affected (e.g., strengthened, diminished, or negated) by the child's diagnosis or the absence thereof.

The following literature review provides an overview of family resilience and contributing factors (i.e., connectedness) that may buffer the impact of adversity and influence a family's ability to cope during times of crisis. We will explore the history and origins of family resilience as well as how certain facets of family resilience, specifically connectedness, may help families raising a child with an NDD weather the chronic stressor that has emerged as a result of the COVID-19 pandemic.

CHAPTER 2

REVIEW OF THE LITERATURE

Overview of Family Resilience

Family resilience is a family's potential to withstand and rebound from adverse situations and prolonged hardship (Walsh, 2003; Walsh, 2016) and it involves the processes and outcomes associated with managing or restoring family system equilibrium after stress or crisis (Henry et al., 2015). Though the construct can be complex, with a multitude of contributing factors, simply put, family resilience is the family's ability to cope and adapt from difficult situations or hardships. Although, it is worth noting that this adapting or rebounding does not equate to a return to the way things were before the crisis, rather it refers to the family's ability to gather, be flexible, and live well despite the adverse experience (Nichols, 2013).

Resilience is relative to situations and can change over time. And whether it is studied at the individual, family, or societal level, resilience is highly influenced by the connections forged through the relationships (Masten & Barnes, 2018) and systems that are present in a person's life (see Figure 1). Since the focus of this study is to learn more about resilience at the family level, we will draw from Masten and Barnes' (2018) description of family. They state that the family is a composition of individuals, each with their own distinct personalities, strengths, and weaknesses that contribute to the group (i.e., family), and that these traits and skills contribute to the family's ability to adapt and overcome difficulty. Times of crisis and adversity offer an opportunity for families to unite to support one another through the challenge they are facing. Though most families are likely to encounter

significant stressors or crises at some point, some families tend to cope and deal collectively together rather than as individuals.

This tendency to collectively deal with adversity may be culturally dependent. For example, according to Chang and colleagues (2015), families in a collectivist minded society, such as those hailing from Southeastern Asian cultures, like Singapore, report positive outcomes (e.g., coping well, hope, optimism) as a result of their drive to deal with crisis together as a group or community. In contrast, families from Western cultures, who tend to be individualistic in their functioning, report valuing individual boundaries and rights within the family during crisis (Dwairi & Achoui, 2010). Though there are no measures or literature to provide definitive support that one culture is better at coping during times of distress, there is some research that examined resilience in individuals of Asian origin and individuals who identified as White and from Western origin (Raghaven & Sandanapitchai, 2019). This study found that participants who identified as Asian or South Asian scored significantly higher on measures of resilience than their White counterparts. This could possibly be attributed to how they cope during stressful events.

Exposure to unusually intense and persistent stressors can induce psychological responses (e.g., burnout, depression, anxiety), physical symptoms (e.g., inflammation, cardiovascular problems), and relational distress (Southwick et al., 2014). For some families the stress may become so excessive that it threatens the family structure and may even result in a breakdown of the family unit (Chang, Neo, & Fung 2015). Therefore, it makes sense to explore family resilience given that it can be a buffer against anxiety and depression in times of stress, and that it can be useful to nurture and practice as a way to potentially help caregivers meet the demands and stressors of parenting (Aivalioti & Pezirkianidis, 2020).

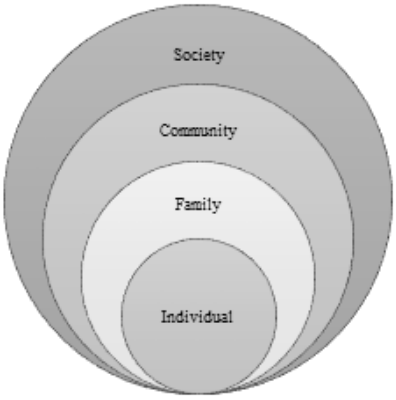
Historical Underpinnings and Waves of Resilience Research

The construct of family resilience has evolved over time. The understanding of family resilience has been guided by knowledge garnered from research on individual resilience, which has progressed through distinct shifts, or waves (Henry et al., 2015). According to Vella and Pai (2019), the first wave of resilience research focused on the "what" questions of identifying the nature of resilience. During this time, the focus was aimed toward looking at both person-level factors and situation or environmental-level characteristics that may influence resilience. As a result, the understanding became that resilience was influenced by the interaction between individual characteristics, personality traits, and familial, community, societal and environmental factors. Today we refer to these as protective factors, individual characteristics and/or environmental/contextual conditions (Dias & Cadime, 2017) that help minimize the effects of adverse events. Once researchers identified a comprehensive knowledge base of the factors comprising resilience, they sought to grow in understanding of *how* resilience develops and in what ways it could be promoted, resulting in the dawn of the second wave of resilience research (Vella & Pai, 2019). In wave two, there was movement toward understanding how the characteristics of resilience (i.e. at the person and environmental level) interact to promote positive outcomes allowing individuals to preserve their mental health and not succumb to mental health distress.

The third wave of resilience research worked toward connecting principles learned from waves one and two and to translate them to interventions that would promote resilience through prevention and intervention studies (Vella & Pai, 2019). The goal was to investigate how to teach or encourage resilience when it may be an underdeveloped motivational force within a person. The fourth and current wave of individual resilience research has adopted a

multidisciplinary approach aiming to capture a holistic understanding of resilience including the contributions from neurological and biological mechanisms (Henry, Morris, & Harrist, 2015, Vella & Pai, 2019;). Vella and Pai (2019) elucidate an important note regarding the movement between waves in resilience research. The evolution of what we have learned does not signify that the work in one particular wave is complete. Rather, they suggest that further exploration into the dynamic interaction between a person's development and the multiple systems (see Figure 1) in which they operate is how we will continue to grow in the understanding of the complexities of resilience.

Figure 1. Family Systems Model



One such complexity lies in how resilience is connected to systems, or relationships, in a person's life (Masten, 2014). The examination of family resilience in some ways has mirrored the trends, or waves, in individual resilience research and the potential parallels will be described below. However, family resilience has been slower to advance as it is a relatively novel conceptualization. As seen in Figure 1, the system adjacent to the individual is the family. The term *family* is representative of a complex system that can be difficult to examine and understand (Maurović, et al., 2020) due to the diverse forms it can take. Because we acknowledge the many variations that occur in families, we will henceforward operate from Lietz's (2006) conceptualization when referring to *family*. This broad definition

suggests that family consists of "at least two or more people who interact in a relationship that they define as familial" (p. 576).

Just as individual characteristics and skills matter in determining resilience, we also know that individuals contribute to the overall functioning of a family. We see this in the second wave of individual resilience research which considered how an individual's resilience interacted with and was influenced by their environment. Since families are one of the most proximate relationships in a person's life, it can often be a positive mediating influence helping its members work through stressful life events (Herdiana, Suryanto, & Handoyo, 2018). Resilience, then, can be a protective factor at both the individual and family levels, with resilience at one level likely influencing the other.

Historical underpinnings and Waves of Family Resilience Research

The distinction between individual and family resilience began in the field of physics and eventually attracted attention from other disciplines such as psychology (Maurović, et al., 2020). The concept of family resilience can be traced back to the early twentieth century around the time of the Great Depression and World Wars when researchers became interested in how the stress of these experiences impacted the coping strategies of families (Maurović et al., 2020). In their review of family resilience, Maurović and colleagues (2020) sought to help the field operationalize the diverse history and trajectory of resilience at the family level. At the time scholars in the field of psychology were largely followers of Freud's psychodynamic perspective and relied on psychoanalysis and the medical model to help explain human behavior. But observations began shifting toward exploring individual differences and strengths. By the 1950's, viewing the person holistically rose in importance and humanistic psychology began to take shape. The progressive views of humanistic

psychology had an appreciation of the whole being (Schneider et al., 2014) which guided the research into exploring the quality of the lived human experience. Through this work it became evident that various systems (i.e., relationships within and among family members) influenced both individual and family functioning. Over the next several years, the research and understanding of these systems shaped general systems theory, ecological systems theory, and family systems theory, all of which helped inform Walsh's family resilience framework, utilized in the current study.

Still, Maurović and colleagues (2020) suggest that there remain conflicting opinions among resilience researchers as to whether resilience is a family characteristic that is either present or not, if resilience is an outcome, or if it is a process that develops over time for positive outcomes. Early exploration into family resilience research proposed that it was a characteristic of the family. But Walsh (2003) argues that there are distinct differences between family resilience and family strengths. Her work suggests that family strengths aid in family functioning but that they may not be able to reduce risk. Thus, proponents of a process-oriented approach favor viewing it as a process that can develop and progress over time because it makes space for variability in the phenomenon rather than focusing primarily on an outcome. As a result of discourse among resilience researchers, the prevailing viewpoint supports treating family resilience as a process, suggesting that family resilience is dynamic and can be practiced, improved, and reliably measured over time.

Here language matters, and in an effort to contribute uniformity in concepts and terminology, as well as to recognize that resilience can be both a process and an outcome, there has emerged a distinction in the literature in the utilization of "resilience" when referring to a process, and "resilient" be used when referring to an outcome-based definition.

In the context of this paper, we will use *resilience,* which is consistent with seminal literature suggesting that resilience is a process and thus is much more than an outcome or end goal to achieve.

Waves of Family Resilience

Family resilience research follows a parallel structure to individual resilience. Similar to individual resilience work, family resilience has also evolved over time, also called waves. But, while individual resilience has progressed through four waves, family resilience is slightly behind and just moving into its third wave of theorization.

Henry, Morris, and Harrist (2015) have outlined the history of family resilience by noting the initial focus, or wave one, explored the characteristics of resilient families and how they navigated through stressors and change. In wave two, researchers focused on advancing the conceptual framework of family resilience by looking closely at protective factors with an emphasis at the family systems-level. This was highly transformative toward advancing family resilience toward a strengths-based framework that we are familiar with today (Masten & Monn, 2015). This second wave distinguished *family protective processes* and *family resilience factors*. *Family protective factors* involve static, or relatively stable, qualities and resources such as suitable housing and caring parent-child relationship interactions. In contrast, *family resilience factors* are illustrated by family strengths that shield a family against the negative effects of crisis and the risks associated with the pile-up of stressors. Walsh (2003) organized these family strengths, or resilience factors, into three primary dimensions corresponding to nine key processes in family resilience: belief system (finding meaning of the adversity, having a positive outlook, transcendence, and spirituality), organizational patterns (flexibility, connectedness, social and economic resources), and

communication and problem solving (clarity, open emotional expression, collaborative problem solving). These distinct factors will be described more below. It was in the second wave that family resilience scholars recognized that there was an interaction of family resilience with the various systems surrounding the family (e.g., social, psychological, economic, biological, cultural/historical). During this wave, clinicians and providers who worked with families became familiar with the deleterious effects that short-term and enduring risks and stressors could have on the family (e.g. divorce, job loss, military deployments, violence, immigration).

As work on family resilience moves into its third wave, Criss, Henry, Harris and Larzelere (2015) propose that research ought to be characterized by the following six characteristics: (a) examining family resilience as involving multiple levels of family systems through a focus on multiple interacting family adaptive systems (e.g., family emotion system, family meaning system) within the broader ecological context; (b) increased depth, breadth, scope, and consistency in family resilience terminology; (c) support for the newly developed family resilience model (FRM) as a basic paradigm for research and practice within which existing or new perspectives of family resilience can be used; (d) a greater emphasis on trajectories and cascades; and (e) enhanced prevention, intervention, and policy approaches.

This study is situated in the third wave of family resilience research, and as such we will seek to explore specific aspects of family resilience and the impact of the COVID-19 pandemic on families raising children with an NDD with the characteristics outlined above, specifically items a and b, in mind and through the lens and vocabulary of the family resilience framework.

Overview of Family Resilience Framework

The family resilience framework, developed by Froma Walsh (2003), was selected for use in this study based on this strengths-based focus on how families function during stress and crises. Developed on a foundation of clinical and social science research, the aim of the family resilience framework has been to recognize family processes that have been shown to reduce stress and mitigate vulnerability while promoting healing and growth through adversity. Through her decades long research and clinical application, the family resilience framework is comprised of three primary factors and nine subprocesses that have been found to be common elements in successful family response to crisis. The three primary factors are belief systems, organizational patterns (including connectedness), and communication and problem solving. Each of these primary factors consists of their own set of key processes (see Table 1; Walsh, 2003; Walsh, 2015).

Table 1

Key Processes in Family Resilience

Belief System

1. Make Meaning of Adversity
   - View resilience as relationally based vs. "rugged individual"
   - Normalize, contextualize adversity and distress
   - Sense of coherence: crisis as meaningful, comprehensible, manageable
   - Causal/explanatory attributions: How could this happen? What can be done?

2. Positive Outlook
   - Hope, optimistic bias: confidence in overcoming odds
   - Courage and encouragement: affirms strengths and focus on potential
   - Active initiative and perseverance (Can-do spirit)
   - Master the possible; accept what can be changed

3. Transcendence and Spirituality
   - Larger values, purpose
   - Spirituality: faith, congregational support, healing rituals
   - Inspiration: envision new possibilities: creative expression: social action
   - Transformation: learning, change, and growth from adversity

Organizational Patterns

4. Flexibility
    - Open to change: rebound, reorganize, adapt to fit new challenges
    - Stability through disruption: continuity, dependability, follow-through
    - Strong authoritative leadership: nurturance, protection, guidance
        - Varied family forms: cooperative parenting/caregiving teams
        - Couple/Co-parent relationship: equal partners

5. Connectedness
    - Mutual support, collaboration, and commitment
    - Respect individual needs, differences, and boundaries
    - Seek reconnection, reconciliation of wounded relationships

6. Social and Economic Resources
    - Mobilize kind, social, and community networks: seek models and mentors
    - Build financial security; balance work/family strains

Communication / Problem-solving

7. Clarity
    - Clear, consistent messages (words and actions)
    - Clarify, ambiguous information: truth-seeking/truth-speaking

8. Open Emotional Expression
    - Share range of feelings (joy and pain, hopes and fears)
    - Mutual empathy; tolerance for differences
    - Take responsibility for own feelings, behavior, avoid blaming
    - Pleasurable interactions; humor

9. Collaborative Problem-solving
    - Creative brainstorming; resourcefulness; seize opportunities
    - Shared decision-making; conflict resolution: negotiation, fairness, reciprocity
    - Focus on goals; take concrete steps; build on success; learn from failure
    - Proactive stance: prevent problems; avert crises; prepare for future challenges

Family resilience is a multifaceted construct (see Table 1). The interplay between all the aspects of family resilience matter in a family's ability to withstand prolonged adversity; however, when measured as a whole it may be difficult to parse out whether some aspects matter more when it comes to a family's ability to rebound or recover from prolonged exposure to challenging situations. By exploring individual aspects of family resilience,

inferences regarding distinctive contributing factors may be uncovered and may help explain why some families adapt in times of adversity and other experience maladjustment. Family related features such as good family management, positive and fulfilling feelings of connection with family, and open family interaction and communication were shown to be negatively associated with child psychological and behavioral problems (Dong et al., 2021). Thus, families who demonstrated higher ratings of these characteristics had children with fewer psychological and behavior difficulties lending support for the idea of identifying individual aspects of family resilience to see if patterns or distinct profiles exist.

In this study, we were interested in the role that connectedness, part of the Organizational Processes within the second of Walsh's (2003) three primary factors, had on families of children with an NDD given the isolation brought about by the pandemic. While each of these processes are important in overall resilience of the family unit, we suggest that family connectedness during the pandemic may be one of the primary ingredients that helped families cope and may have been the most threatened aspects of resilience because of the isolation. There is increasing awareness being directed toward safe, stable, and nurturing relationships and how they contribute to resilience. There is evidence to suggest that strong emotional supports through family resilience and connection are associated with children that are resilient and thrive despite facing adversity (Garner & Yogman, 2021). In fact, an analysis of data from a 2016–2017 National Survey of Children's Health found that children with high adversity, indicated by four to nine Adverse Childhood Experiences or ACEs, but high family connection and resilience had better functioning than children with low adversity, indicated by zero ACEs, but low family connection and resilience (Bethell et al., 2019). Indeed, for many children their primary experience with safe, stable, and nurturing

relationships will be with their family because of the close, intimate, and emotionally powerful environment (Duncan et al., 2020). We know that this special relationship has a potent and enduring influence (Hambrick et al., 2021) and has the power to promote or hamper resilience (Duncan et al., 2020); therefore, it stands to reason that family connectedness during the pandemic, an enduring time of adversity, should be explored.

Connectedness

Family Connectedness is defined by Walsh (2016) as the structural bonding among family members and refers to a family's closeness, support, warmth, or responsiveness to one another (Manzi &Brambilla, 2014). That is, this conceptualization means they enjoy time together, like being involved in each other's lives, share in the functioning of the home, and overall have fun together. The comfort and security provided by warm and caring relationships is crucial in times of stress when anxiety and upset can often lead to conflict and feelings of being overburdened. It is during these times of stress or crisis where families may experience the basic need for relatedness or connectedness (Walsh 2016).

Findings from prominent family resilience experts suggest that connectedness is a lifeline for resilience and that family relationships act as "shock absorbers" during times of trouble (Walsh, 2016). Of course, the opposite is also true; an absence of such relationships may increase the risk for negative outcomes (e.g., emotional, or behavioral problems; Foster et al., 2017). Connection with a caregiver, at the biological, emotional, and physical levels, is a primal need early in life when infants and children are highly dependent on others. In addition to being foundational to survival, these relational experiences help children establish their sense of safety and influence their ability to tolerate and manage stress (NRC & IOM, 2009). We have also learned that the connectedness, in other words the closeness, support,

warmth, and responsiveness, forged within these close relationships contributes to resilience which is a protective factor against adversity and stress.

Family resilience experts often liken the family to a team where every member has a role and contributes to functioning of the family and the home environment. Walsh (2016) notes that "good teamwork facilitates resilience under stressful conditions" (p. 75). We anticipate that for some families it was difficult to share the burden of all the role shifts and responsibilities that became part of pandemic life (e.g., increased household chores, supervision of children) which may negatively impact ratings of connectedness. There is a myriad of contributing reasons why families may have been unable to share in the responsibilities, perhaps the caregiver is a solo parent, or the children were young and developmentally or physically required extra amounts of supervision. Family members who feel understood, loved, wanted, and attended to by other family members may be more likely to experience stronger family connectedness. This may be characterized by caregiver and child interactions that are largely free from conflict, hostility, and mistrust (Lezin et al., 2004) all of which may have been at risk given the added stressors from the pandemic.

Cross-Cultural Considerations and Family Connectedness

Family is an important support system that is central to the health and well-being of people regardless of culture (Stuart & Jose, 2014). Though much of the family resilience literature is constructed on white, middle-class family systems (McCubbin & McCubbin, 2013) there is no one-model-fits-all of family health (Walsh, 2003), and preferences for closeness may be dictated by cultural norms. These social norms act as rules or guidance of how to behave and interact with others by providing a mental template on how to interpret situations, how to feel about the situation, and then what to do based on this information

(Reese et al., 2019). And, despite the foundation of Western centric family functioning ideals (e.g., personal achievement, autonomy, independence), family resilience, in general, has been identified cross culturally. In fact, family connectedness, an aspect of resilience, was found to be higher in Eastern than in Western countries (Dwairi & Achoui, 2010). A longitudinal study of youth connectedness within the Māori community, indigenous people of New Zealand, found that family connectedness is an essential aspect of functioning and extends beyond those in the nuclear family to include multiple generations of extended family and friends who each hold roles and responsibilities in the taking care of the community (Stuart & Jose, 2014). Youth in the Māori community were asked to complete self-report measures one year apart for three years and the findings consistently demonstrated a link between higher ratings of family connectedness with positive health outcomes and overall wellbeing (e.g., self-esteem, higher academic achievement, and fewer behavioral concerns). The association between family connection and positive functioning is evident in Asian communities as well. In 2003 a global outbreak of severe acute respiratory syndrome (SARS) swept across Asia and 29 countries infecting 8,096 people and claiming 774 lives (SARS (10 years after), 2016). Communities were impacted by quarantines and isolation like what occurred during the COVID-19 pandemic, including Singapore, where healthcare workers reported a reliance on the physical resources, emotional connection, and psychological support from their families to help them get through the difficult time and increased stress brought about by being quarantined away from their families (Chang et al., 2015).

The positive health outcomes linking family resilience and wellbeing, specifically the role of connectedness, especially in adolescent samples, can be attributed to the foundation that is created by socializing family members through ways of thinking (i.e., schemas;

McCubbin & McCubbin, 2013), family values (Lahlah et al., 2013), and in the transmission of intergenerational cultural identity (Stuart & Jose, 2014; Tam, 2015). The ways of thinking, values, and identity are passed on intergenerationally through relationships and by sharing stories of the family's experiences, successes, and accounts of overcoming adversity. These practices have been shown to help younger generations build hope and positive change (Landau, 2013) and essentially contribute to family resilience and connectedness. Families of all ethnicities and cultures are deserving of representation in family studies and for their data to be interpreted in context to their schemas or identities (i.e., values, beliefs, practices, and expectation; McCubbin & McCubbin, 2013). Though it is beyond the scope of this paper, future research has an opportunity to contribute to family studies by exploring the effects of the pandemic on family resilience and connectedness with a more focused lens toward underrepresented groups of people.

Pandemic Impact on Connectedness

The COVID-19 pandemic posed many risks to families and increased demands on how they parented and functioned as a family. Parenting is hard. And parenting during a pandemic may have introduced or exacerbated problems within the family's ability to depend on one another and adapt to the added pressures caused by the pandemic. Indeed, not only is family connectedness key, but we expect that it underwent significant stress and that there were barriers to optimal connectedness. Caregivers found their roles overlapping often without specified boundaries as they tried to manage the roles of parent, employee, teacher, and more all while coping with the threats to their family's health and safety during the pandemic.

Economic stressors, like financial insecurity and resource scarcity, added to stress levels for families as well. In fact, more than 10 million children had a family member who was unemployed or experienced wage loss because of the economic impact of the pandemic (Zippel & Sherman, 2021). And, for Black, Indigenous, and people of color (BIPOC) in the United States, the rates of significant financial hardship and health disparities are staggering (Chen & Krieger, 2020; Ruprecht et al., 2021). A collaborative endeavor between NPR, the Robert J. Wood Foundation, and the Harvard T.H. Chan School of Public Health confirmed in their 2020 study that families of Black, Latinx, and Native American communities have faced disparate health and economic effects that were exacerbated by the pandemic. The study found that 72% of Latinx, 60% of Black, and 55% of Native American families reported serious financial difficulties compared to 37% Asian and 36% White families. These families also experienced stressors related to affording health care services with a high rate of respondents noting that they experienced negative health consequences as a result. All of these are significant stressors that threaten to weaken the family's ability to recover and cope. We are only just beginning to explore how the persistent nature of pandemic-related stressors have impacted the resilience and connectedness within the family. Family resilience and connectedness is not a unique U.S. family experience, though it is often defined and reported through the lens of Westernized cultural and context derived constructs (Ungar, 2006). It is worthwhile to recognize how understanding and interpretation may be influenced by White and Westernized perspectives, social and cultural values and that implications may not be accurately generalizable to all cultural and ethnically diverse families.

Disaster research in the United States often focuses on natural disaster (e.g., hurricanes, tornadoes, floods) and how it affects communities because of the increase in

frequency and extensive data available. A review of post-disaster resilience trajectories by Lai, Lewis, Livings, La Greca and Esnard (2017) found that deficits in family connectedness among hurricane affected children was a risk factor in the trajectory of their functioning and resilience. Family connectedness, considered a social support here, was the primary protective factor that was identified across the studies. Gender also influenced risk for experiencing chronic symptoms of stress (i.e., PTSD) and determining how they responded to disasters. Girls were more likely to face chronic symptoms of stress rather than a trajectory of resilience. These findings suggest a need to consider how social support both inside and outside the family can be addressed and nurtured during emergent events.

The bearing of these events (e.g., emergencies, disasters, catastrophes) on families raising a child with an NDD may be even greater. Parents of children with ASD report higher levels of parenting stress than parents raising a child without an NDD (Hartley et al., 2016). However, there is a dearth of understanding in the literature about how families raising a child with an NDD have been coping during the extraordinary time of the pandemic. What we do know is that individuals with ASD are particularly vulnerable to loss of connectedness because of diagnosis-related difficulties in appraising situations, adapting to new routines, and having reduced access to medical treatment for other chronic health conditions because of pandemic related quarantines and shutdowns (Tokly Latzer et al., 2021). We are hopeful that our exploration of connectedness will help providers understand how to best support families raising children with an NDD as we continue to navigate the effects of the COVID-19 pandemic for the foreseeable future.

Pandemic Impact and Disabilities

It is anticipated that the impact of the pandemic may be greater on families that have children with an NDD than those who do not because these families already face a unique set of stressors (Bayat & Schuntermann, 2013) compared to families raising a neurotypical child (Karst & Van Hecke, 2012). Though a child with an NDD or with behavioral difficulties is a beloved and valued member of the family, there are unique stressors that a family faces in managing their child's diagnosis and in meeting their needs. Families may experience challenges in the marital or caregiving relationship, conflict between siblings, and in adjustment in adapting to family routines (Greeff & Van der Walt, 2010). An NDD diagnosis often adds significant time pressures and financial strain. Children with an NDD diagnosis often encounter more doctors and specialist appointments which contributes to increased healthcare costs, need for specialized schooling, supports, and activities (Karst & Van Hecke, 2012). All of this results in a reduction of personal time for caregivers which can contribute to and increase the risk of depression as well as conflict within interpersonal or marital relationships, which in some cases may result in divorce (Greeff & Van der Walt, 2010). Parenting a child with ASD has been linked to higher levels of parenting stress, psychological distress, and mental health problems in caregivers (Argumedes et al., 2018). A recent qualitative study exploring families raising a child with ASD found that a child's success or failure was directly related to how their caregivers coped during the isolation of the pandemic (Tokatly Latzer et al., 2021). Three themes of caregiver coping emerged from this study: (1) accommodation of needs; caregivers tried to anticipate their child's needs to achieve harmony in the household, (2) exposure to information; caregivers reported monitoring the news and other information about the COVID-19 virus to mitigate fear and anxiety, and (3) family influences: attending

to the family dynamics that had to be adjusted due to the increased togetherness. Findings from this study suggest that attending to caregiver support may be the best way to help children with an NDD.

In a study by Jones and colleagues (2020) it was noted that neurotypically developing siblings of children with ASD are at an increased risk for mental health concerns (e.g., anxiety and depression) as their development and adjustment may be negatively influenced by their sibling's behaviors. They describe that these negative impacts may stem from observing and experiencing their sibling's aggressive behaviors and witnessing their caregiver's stress from managing the challenges of the child with ASD. Of course, it is also worth noting that not all differences between families with children diagnosed with an NDD and families without children with such diagnoses are negative. Rather, Jones et al. (2020) report that many neurotypical siblings of children with an NDD are described as having positive self-concepts and demonstrate greater empathy and patience compared with exclusively neurotypical sibships. Perhaps these positive outcomes may also be related to resilience. Despite the existence of family stressors, these family members are socially succeeding, perhaps even because of the stressors they have learned to cope with in positive ways.

Previously, in the introduction of this paper, we discussed how routines are beneficial and often a core component of parent training programs aimed at managing behavior problems that are hallmark features of an NDD. However, there are downsides of routines that families must contend with and navigate. Daily life is not static and there are circumstances that arise that require alteration to daily and situational routines, which may elicit challenging behaviors from children with an NDD (Bull et al., 2015). COVID-19 introduced many changes to family routines with many children having to learn/attend school from home, adapt to social distancing directives,

and constant cancellation of plans. Each of these instances would be disappointing for anyone, but for children with an NDD who often rely on the predictability afforded by functional routines, instances like these may have resulted in an increase in negative behaviors (e.g., tantrums, property damage, self-injurious behaviors like head banging, biting, and scratching). Though much of the research involving family functioning of children with ASD has appeared fatalistic, as researchers begin to evaluate families through the lens of resilience, their work is revealing a more positive side of life for these families. One of the earliest studies to consider family resilience in families of children with ASD found that around 40% of families reported feeling stronger as a family because of having a child with an NDD (Bayat & Schuntermann, 2013). These data offer hope that perhaps high levels of family resilience may protect families raising a child with an NDD, and these families may emerge from the COVID-19 pandemic with similar feelings of strength.

The dynamic changes to everyday life that were precipitated by the COVID-19 pandemic are just starting to be explored, especially in families raising a child/children with an NDD. Much of what this writer has observed has been anecdotal in nature and limited to the child development clinic where caregivers sought therapeutic services. However, it was while working with these families that a distinct differentiation emerged between how some families were functioning well despite the extraordinary disruption and some were not. This particular clinic serves families seeking therapy to address their child's disruptive behaviors using skills taught with Parent-Child Interaction Therapy (PCIT). Common diagnoses for this clinic population include ASD and ADHD. In April 2020 in-person services were halted and the majority of patient families transitioned to teletherapy. The isolation and quarantine, though important preventative measures for personal and public health safety, posed

challenges to engaging in social interaction and brought to the forefront the state of connectedness of immediate family members living in the home. That is, if connectedness within the family was weak to begin with, it became glaring, and problems became unavoidable. This contrast was seen with some families enjoying the prolonged time together. Some parents were able to practice their special play time (a key tenant of PCIT where caregivers are instructed to spend focused one-on-one time playing with their child to practice skills from their PCIT sessions) more regularly since fewer demands were being made on their schedules. Others enjoyed the slower pace to their lives which improved their patience and reduced parenting conflict with their child. However, for some families relational conflict bubbled to the surface and in combination with the multitude of stressors, their relationship deteriorated, and they chose to divorce. This real-world, clinical experience was the impetus behind this project.

Gap in the Literature

The concept of family resilience in light of crisis is not new; however, the COVID-19 pandemic is, and therefore provides an opportunity for exploration into the cumulative impact that the pandemic has had on families and to focus on how they are coping during this enduring health emergency. Specifically, this study explored the uncharted territory of understanding how the pandemic has uniquely impacted families raising a child(ren) with an NDD. Families of children with an ASD diagnosis are at greater risk of mental health related concerns (e.g., anxiety, depression) which can be attributed to a combination of stressors and family adjustment difficulties (Weiss et al., 2014). We were interested in exploring whether connectedness was a pathway to family resilience despite potentially stressful COVID-19 experiences including public health mandates. The need for mental health services rose

significantly during the early stages of the pandemic (Coley & Baum, 2022) and providers will benefit from knowing specific mechanisms by which family resilience might be maintained in the face of such a catastrophe (Prime et al., 2020).

Other Determinants of Family Resilience

Although family resilience and pandemic impact were our primary variables of interest, we recognized that other variables may be related to both resilience and pandemic impact and therefore should also be explored as part of this project. Household income has been shown to impact a family's relationship and interaction. Poverty and income instability are known to be exacerbated by, but also intensify, mental health concerns (e.g., anxiety, depression), substance use, and family relationship distress (Taylor, 2013, Walsh, 2012). Poverty and constraints around financial circumstances introduce stress that may reduce a caregiver's ability to have an effective presence that nurtures, monitors, and provides consistent discipline for their child (Mackay, 2003). In families raising a child with a disability, the stress that financial instability contributes can be highly impactful to the health, emotional well-being, physical environment, and family interaction. It is estimated that 28% of children with disabilities live in families whose income falls below the poverty threshold set by the United States government (Knestrict & Kuchey, 2009). Income has also been shown (Hunt et al., 2021)to impact how these families handle stress, with higher income providing opportunity for more choices available to assist in coping (e.g., hiring a babysitter, ability to order food out, entertainment). Financial stress may have been a common experience during the pandemic, but for those with preexisting financial hardship, the consequences may be far greater (Prime et al., 2020).

The Current Study

Our understanding of the factors that promote family resilience in the aftermath of disaster and catastrophe is growing; however, there remains a need to add to the scholarship on how family resilience processes can support individuals and families facing challenges (Masten, 2018), especially in families of children with NDD. In family resilience studies that have focused on families with NDD, specifically ASD, it has been shown that stress can impede resilient family functioning (Cripe, 2013). With 1 in 54 children in the United States likely to be diagnosed with ASD each year (Centers for Disease Control and Prevention, 2020), there is an increasing need to understand how to support these families so they can optimally function, be the best that they can be, and even flourish. Despite advancing knowledge surrounding ASD, we know little about how the pandemic has affected families raising a child with NDD. This project was one of the first known studies investigating the impact of the COVID-19 pandemic on family resilience within families raising a child with NDD.

Aims and Research Questions

In light of the studies and theories described above, the primary goal of this study was to grow our understanding of the impact of the pandemic and how it affected families of children with an NDD compared to their neurotypical peer families. A second goal of this study was to test if there are any distinct differences in family resilience and ratings of connectedness between families raising a child with NDD and those who are not. Thirdly, we were interested in understanding whether family resilience and connectedness are associated with pandemic impact. And finally, we tested whether relationships between family

resilience, connectedness, and pandemic impact is moderated (e.g., strengthened, diminished, or negated) by the child's diagnosis.

To address the aims of this study, our research questions were as follows:

Aim #1. Pandemic Impact and Group Membership:

1a. Do families raising a child/children with NDD report greater impact from the pandemic compared to families raising a neurotypical child/children?

1b. Do families raising a child/children with NDD report greater indirect pandemic impact compared to families raising a neurotypical child/children?

1c. Do families raising a child/children with NDD report greater direct pandemic impact compared to families raising a neurotypical child/children?

Aim #2. Family Resilience and Group Membership:

2a. Is there a difference in ratings of overall family resilience between families raising a child/children with NDD and those raising a neurotypical child/children?

2b. Is there a difference in ratings of connectedness, an aspect of family resilience, between families raising a child/children with NDD and those raising a neurotypical child/children?

Aim #3. Relationship between Family Resilience and Pandemic Impact:

3a. Is there is a correlation between overall family resilience and reported pandemic impact?

3b. Is there a correlation between connectedness and reported pandemic impact?

3c. Is there a correlation between overall family resilience and indirect pandemic impact?

3d. Is there a correlation between connectedness and indirect pandemic impact?

3e. Is there a correlation between overall family resilience, connectedness, pandemic impact (cumulative, direct, indirect) and group membership (NDD child or no NDD)?

Aim #4. Influence of Group Membership and Family Resilience and Pandemic Impact:

4a. Does group membership (NDD child or no NDD) moderate the relationship between family resilience and pandemic impact?

4b. Does group membership (NDD or no NDD) moderate the relationship between connectedness and pandemic impact?

CHAPTER 3

METHODOLOGY

Approach

Data from this study were part of a broader project aimed at examining caregiver perspectives of how families coped during the first year of the COVID-19 pandemic regarding child social support, school functioning, family engagement in child/schooling, and child/family utilization of therapy services. The purpose of this study was to explore how the pandemic impacted families raising a child with an NDD during the first year of the COVID-19 pandemic. We also sought to investigate the impact of the COVID-19 pandemic on family resilience, with a specific focus on connectedness, within families raising a child with NDD.

Participants

The study recruited parents or legal guardians (henceforth caregivers) of children (< 18 years old) with or without an NDD (N=113; *n*=58 for NDD; *n*=55 for non-NDD; Table 3). This study relied on the Diagnostical and Statistical Manual of Mental Disorders 5th edition (DSM-5) categorization of an NDD to include intellectual disorders, autism spectrum disorder, attention deficit hyperactivity disorder, and specific learning disorders.

Data Collection Procedures

Participating families were recruited through advertising in a developmental pediatrics clinic at an academic-affiliated medical center in the Midwest, local parenting groups on social media, postings within community-based autism providers and advocacy groups, and in a monthly ASD family support newsletter published through a local children's hospital. Study enrollment and all research procedures occurred online, without researchers

present, and were completed between January and July of 2021, approximately 9-14 months into the COVID-19 pandemic.

Recruitment materials instructed interested caregivers to follow a link to an online survey through REDCap (Harris et al., 2009), which contained information about the study including how to contact the research team, confidentiality practices, consent information, and surveys. Participants consented to the study by reading the consent information and checking "yes".

Participants were informed that they could skip any question if they did not wish to provide an answer, and they could discontinue the survey at any point. Caregivers were asked to report on each child in their home. Seventy-one of 113 families had more than one child in their home, and those families with at least one child with the diagnosis of an NDD were included in the NDD diagnosis group. At the conclusion of the survey, participants were provided with an opportunity to submit their email address to enter a drawing for a $25 Amazon gift card.

All study procedures were reviewed and approved by the Institutional Review Board at the University of Kansas Medical Center (KUMC). Researchers at the University of Missouri-Kansas City were granted a request to rely on the KUMC IRB. Participant gift cards were provided by the Center for Child Health and Development at KUMC.

Measures

Demographic Information. Demographic data included information about the caregiver and child/ren such as sex (binary coding; 0 = female, 1 = male), age, race, and ethnicity as well as family characteristics such as number of caregivers at home, income, household size, child neurodevelopmental diagnosis, and child/family utilization of therapy

services. Regarding diagnostic reporting, the caregiver was asked to report on all diagnoses; however, no rank order for primary diagnosis was offered.

Pandemic Impact. The Epidemic – Pandemic Impacts Inventory Brief Form (EPII-B; Grasso et al., 2020a) is a newly developed 30-item inventory of questions pertaining to pandemic-related experiences in several personal, social, and work-related life domains. The EPII-B is derived from the full Epidemic-Pandemic Impacts Inventory (EPII; Grasso et al., 2020b). All questions except for questions 28 and 30 measure negative or adverse experiences; consequently, questions 28 and 30 were reverse scored. Each item had a response set of "0 - Did not happen", "1 – Happened but no impact on me or my family", "2 – Some impact on me or my family", "3 – A lot of impact on me or my family", or "4 – extreme impact on me or my family". A total score was calculated by summing items 1-30.

Psychometric properties for the EPII-B are being established; however, Grasso and colleagues (2020c) have published preliminary findings that indicate that the full EPII measure is both practical and suitable in measuring pandemic-related outcomes. We expect that the data from this study will contribute to the development of psychometrics for this measure. Indeed, it is common within the field of disaster and trauma psychology for exposure checklists to be developed to assess exposures relevant to the nature of specific events.

We observed that questions within the EPII-B appeared to reference both direct and indirect ways families have been impacted by the COVID-19 pandemic. We defined direct impacts as something unavoidable that occurred due to the pandemic (e.g., job layoff), and indirect impacts as disturbances that were more secondary effects of the direct impacts, such as relational conflict or distress. The primary (JC) and secondary author (EH) independently

reviewed items from the EPII-B for placement into direct and indirect categories; items were sorted with 100% agreement (see Table 2). In this study, the EPII-B demonstrated good reliability (Cronbach's $\alpha = .85$) for cumulative pandemic impacts, good reliability for indirect impacts ($\alpha = .82$), and acceptable reliability for direct impacts ($\alpha = .69$).

Table 2

EPII-B Questions

Indirect	Direct
I or another caregiver had more conflict with or was harsher in disciplining my child or children	I or someone in my home was laid off, furloughed, had to close a business, or had reduced work hours
There was an increase in verbal or physical conflict with a partner or spouse	I lor someone in my home had to work in close contact with people who might be infected
There was an increase in verbal or physical conflict among other family in my home	I or someone in my home had an increase in workload or work responsibilities
My child[ren] had more frequent or severe behavioral or emotional problems (for example, mood, anxiety, sleep, nightmares)	I or someone in my home provided direct care or services to people who had the disease
I or someone in my home had more frequent or severe mental health problems, sleep, or use of alcohol or substances	A child or teenager/young adult I care for could not go to school or needed home instruction
My family enjoyed more quality time together, paid more attention to personal health, or made new connections with one another or with friends	Childcare or babysitting was unavailable to me or someone in my home when needed
I found greater meaning and was more effective in my work, school, or friendships than before COVID-19	I spent a lot more time taking care of a family member most days
I or someone in my home got less exercise, spent more time sitting down, or ate more junk food	My family had to move, relocate, was evicted, or became homeless

My family was unable to pay for or get enough food or clean water

My family was unable to pay important large bills like rent or utilities

My family had trouble getting places due to less access to public transportation or concerns about safety

I or someone in my home did not have the ability or resources to talk to or see family or friends while separated

My family had to cancel or could not attend important celebrations (such as weddings) or religious ceremonies or funerals

I or someone in my home was
unable to be with a close family member who was hospitalized, in a nursing home, or in critical condition

I or someone in my home was isolated or quarantined due to possible exposure to the disease, symptoms, or increased risk

I had limited physical closeness with my child or loved one due to concerns of infection

I or someone in my home was unable to access or was less satisfied with mental health treatment or therapy

I or someone in my home could not get enough medication or medical treatment for a chronic illness or pain

I or someone in my home had important medical procedures
cancelled or was unable to access medical care for a serious condition

I or someone in my home tested positive for COVID-19 and had severe symptoms

	A close friend or family member died from COVID-19 or related complications
	I or someone in my home was harassed or blamed for causing or spreading COVID-19, or was denied or unable to access services or treatment for COVID-19 because of my race/ethnicity

Family Resilience. The Walsh Family Resilience Questionnaire (WFRQ; Walsh, 2015) is a 32-item questionnaire with a 5-point response set ranging from 1-rarely/never to 5-almost always. Respondents were asked how their families deal "with crises and ongoing challenges." The WFRQ scale is comprised of three primary domains: belief systems, organizational patterns, and communication and problem solving. Of the 32 items, 13 items relate to the domain belief systems, nine items reference the domain organizational patterns, and 10 items correspond to communication/problem-solving. An overall family resilience score was calculated to provide a single score for overall perceived family resilience by summing each of the participants' responses to the 32 items, with higher scores indicating greater family resilience. In this study, the WFRQ demonstrated excellent internal reliability (Cronbach's $\alpha = .96.$, $M = 119.66$, $SD = 23.06$).

Connectedness. To measure connectedness, we used a subset of questions from the Walsh Family Resilience Questionnaire (WFRQ; Walsh, 2015). The Walsh Family Resilience framework has three primary factors and nine subprocesses as outlined in Table 1. For connectedness, a subprocess of organizational patterns, questions 15, 17, and 18 capture family response/behaviors consistent with our selected definition of connectedness. According to Walsh (2016), connectedness refers to structural bonding among family members and describes a family's closeness, support, warmth, or responsiveness to one

another (Manzi &Brambilla, 2014). We created a composite score for connectedness by adding the three questions listed above from the WFRQ that prior research has shown to be directly related to family connectedness (Duncan et al., 2020). In this study, the connectedness items had acceptable reliability (Cronbach's α = .75, *M* = 3.82, *SD* = 1.03).

Data Analysis

All data analyses were conducted using SPSS 27. In order to determine the minimum number of participants needed to achieve adequate power (e.g., .80) to reach a significance level of $p < .05$, an a priori power analysis was conducted using G*Power software (Faul et al., 2007). For a medium effect size of .5, a total sample size of *N*=102 with two equal sized groups of *n* = 51 was determined to be sufficient. In sum, the current study had a total of 113 participants (*n*=58 for NDD group; *n*=55 for non-NDD group), so the study had sufficient power to detect meaningful differences between groups.

Preanalytic Considerations

Review of participant data revealed some instances of incomplete or missing survey responses. Although 118 caregivers initiated participation, five cases were removed from the dataset and not considered for inclusion because their responses were entirely missing, resulting in a final sample size of 113 families. Further review discovered that 40, or 57.14%, of the 70 variables of interested to this study had at least one missing value equating to 2.78% of overall missingness. This means that as many as 7 participants (range: 3-7) in the sample would have been omitted from analysis if a listwise deletion method were used. Listwise deletion has been a commonly utilized method to address missing data, but we relied on guidance from Manly and Wells (2015) to use Multiple Imputation to address missing data, thereby conserving the data in our modest sample. According to Little's MCAR

test, all missing data were missing completely at random (χ^2= 1294.74, *df*=1238, *p*=.13). Next, missing data were estimated using Multiple Imputation (MI). Data were primarily missing due to item nonresponse on the Walsh Family Resilience Questionnaire. Missingness may be attributed to survey fatigue, discomfort with the nature of the questions, or environmental disruptions. Default MI options were chosen within SPSS to generate 5 imputed datasets and were based in accordance with advice provided in the paper by Manly and Wells (2015) that suggests the number of imputations "should be at least equal to the percentage of incomplete cases." A visual inspection of imputed values compared reasonably to observed values, and analyses were conducted using pooled data according to Rubin's (1987) rules.

Histograms were evaluated as well as descriptive statistics (e.g., kurtosis, skewness) for all variables and indicated normal distributions. Relevant demographic data were evaluated through means (*M*), standard deviations (*SD*) and are presented in Tables 3 and 4. Due to the categorical nature of the income variable, we created a binary variable based on the 2021 poverty guidelines set forth by the Department of Health and Human Services (HHS; *2021 poverty guidelines*, *2021*). According to the guidelines, the poverty cutoff is $26,500 for a family of four, which is consistent with family size of our sample. Therefore, the income variable was dichotomized into those who had income below $29,999 (0) and those above $30,000 (1).

Zero-order correlations were conducted between key family characteristics (income /poverty level, number of children in the home, and number of caregivers in the home) to explore which, if any, covariates ought to be included in the analysis. No correlations were

identified between family characteristics and pandemic impact (cumulative, indirect, or direct) or family resilience and connectedness.

Group membership was determined by the caregiver's response to raising a child with an NDD or not (no = 0, yes = 1). Prior to examining our study aims, we assessed for group level differences among key demographic variables in the sample (i.e., income/poverty level, number of children in the home, number of caregivers in the home). There were no significant differences between the two groups that identified covariates to consider in analyses for our research questions.

Additionally, differences in treatment utilization within the NDD group was explored. We anticipated that this would identify if some underlying differences existed that would warrant further analysis. A binary variable was created to explain a family's utilization of therapy services during the pandemic: therapy was offered and engaged in virtually and non-therapy seeking (nonuse=0, treatment use=1; Table 5). Zero-order correlations between treatment utilization and key variables of pandemic impact (i.e., cumulative, indirect, direct), family resilience, and connectedness were conducted. No significant correlation existed between treatment utilization the key variables of pandemic impact or family resilience (see Table 6)

Analytic Plan

To evaluate if there are differences in how the pandemic has impacted (cumulative, indirect, and direct) families raising a child with an NDD compared to those who are not, independent samples *t*-tests were conducted comparing the cumulative, indirect, and direct scores from the Epidemic-Pandemic Impact Inventory-Brief questionnaire between the NDD group and the non-NDD group.

Next, to evaluate if there was a difference in ratings of overall family resilience between families raising a child with NDD and those raising a neurotypical child/children, an independent samples *t*-test was performed. This statistical test was utilized to compare the overall total scores from the Walsh Family Resilience Questionnaire between the NDD group and the non-NDD group. Then, to evaluate if there was a difference in ratings of connectedness, an aspect of family resilience, between families raising a child with NDD and those raising a neurotypical child an independent samples *t*-test was performed. This statistical test compared the connectedness subscale from the Walsh Family Resilience Questionnaire between the NDD group and the non-NDD group.

To evaluate if a relationship existed between overall family resilience and pandemic impact (cumulative, indirect, and direct), the following relationships were examined using Pearson correlations: (1) family resilience and cumulative pandemic impact, (2) connectedness and cumulative pandemic impact, (3) family resilience and indirect pandemic impact, (4) connectedness and indirect pandemic impact, and (5) relationship between group membership (NDD or non-NDD) and family resilience, connectedness, cumulative, indirect, and direct pandemic impact.

And finally, to evaluate if group membership (NDD or non NDD) moderated the relationship between family resilience on pandemic impact, a Baron and Kenny moderation analysis was conducted. Whether the type of impact analyzed was cumulative, direct, or indirect impact depended on findings from analyses in Aim 1-3. To examine moderation, a multiple linear regression was performed. The independent variables in the regression were family resilience scores, group membership, and the interaction between these two variables.

CHAPTER 4

RESULTS

Demographics

Caregivers of children between the ages of 0 – 18 with and without a NDD were recruited from a developmental pediatrics clinic, online caregiver forums on social media, a local children's hospital newsletter, and within community-based autism providers and advocacy groups. A total of 113 families participated with only one caregiver reporting from each family. Caregivers had a modal age between 30-39 years and 96% were female (female =109, male = 2). Additional caregiver and household characteristics are reported in Table 3.

Among 113 families, 55 participants (49% of the total sample) were caregivers of at least one child with a neurodevelopmental disability (NDD). Children within these families presented most frequently with Autism Spectrum Disorder (ASD; 48.61%) or Attention Deficit Hyperactivity Disorder (ADHD; 33.33%). Length of diagnosis varied among the families, but a plurality (31.94%) had been diagnosed within the past 2-4 years. (Table 4).

Table 3

Demographic characteristics of participants

Variable	Non-NDD Group	NDD Group
Families (*n*)	58	55
Caregiver Reporter Gender		
Female (*n*)	58	51
Male (*n*)	-	2
Caregiver Reporter Age (mode)	30-39 years	30-39 years
Race & Ethnicity (%)		
White	44	47
African American/Black	9	4
Asian	2	2
Middle Eastern	1	-
Native Hawaiian/Pacific Islander	1	1
American Indian / Native Alaskan	-	-
No answer	1	1

Other caregiver in home (SD)	1.89 (.67)	2.07 (.63)
Caregiver Relationship Status		
Single/Never married	4	4
Married, or in domestic partnership	45	45
Widowed	1	1
Divorced	5	4
Separated	3	1
Caregiver Sexual Orientation		
Straight/heterosexual	52	46
Lesbian	-	-
Gay	-	-
Bisexual	4	8
Prefer not to answer	-	1
Household Income		
Mean	60-69,999	60-69,999
Mode	90,000+	90,000+
Above Poverty Line	86.2%	87.3%
Below Poverty Line	13.8%	12.7%
Number of Children in the Home (SD)	1.83 (1.03)	2.09 (.95)
Child Age (SD)	7.75 (4.28)	9.76 (3.81)

Table 4

NDD Group Diagnostic Information

Variable	n	Percent
Number of Families Raising a child with NDD	55	
Number of Children within the NDD families	72	
Diagnosis		
ASD	35	48.61%
ADHD	24	33.33%
ID	1	1.39%
Internalizing Disorder	4	5.56%
Conduct Disorder	1	1.39%
Cooccurring diagnoses (ADHD/Anxiety, ASD/ADHD)	6	9.72%
Length of Diagnosis		
Less than 6 months	4	5.56%
6 months - 1 year	7	9.72%
1-2 years	16	22.22%
2-4 years	23	31.94%
4+ years	18	25.00%
unknown	4	5.56%

Table 5

Therapy Utilization

Treatment seeking behaviors	n	%
Virtual therapy	24	43.63%
Did not utilize therapy	30	54.55%
No answer	1	<1%

Note: Therapy utilization during the first year of the COVID-19 pandemic

Table 6

Correlations between predictors in participants seeking therapy

Variable	1	2	3	4	5
1. Therapy Seeking	-				
2. Walsh Total	-.13	-			
3. Connectedness	-.11	.80**	-		
4. Cumulative Impacts	.17	-.96	.15	-	
5. Indirect Impacts	.13	-.47**	-.31	.69**	-
6. Direct Impacts	.14	.03	.10	.96**	.51**

** Correlation is significant at the 0.01 level (2-tailed)

Aim #1. Pandemic Impact and Group Membership

Aim 1a: Overall Pandemic Impact. An independent samples *t*-test was conducted to compare the overall pandemic impact scores for the NDD and non-NDD groups. There were no significant differences in scores for NDD (M = 37.53, SD = 17.40) and non-NDD families (M = 34.46, SD = 17.35); $t(108) = -.93$, p = .36, two tailed). The magnitude of the differences in the means (mean difference = 3.07, 95% CI: -.57 to -1.26) was very small (eta squared = .008).

Aim 1b: Indirect Pandemic Impact. An independent samples *t*-test was conducted to compare the indirect pandemic impact scores for the NDD and non-NDD groups. There was no significant difference in scores for NDD (M = 10.76, SD = 5.11) and non-NDD families (M = 8.76, SD = 5.63); $t(111) = -1.94$, p = .053, two tailed). The magnitude of the differences in the means (mean difference = 2, 95% CI: -.57 to -1.26) was small (eta squared = .03).

Aim 1c: Direct Pandemic Impact. An independent samples *t*-test was conducted to compare the direct pandemic impact scores for the NDD and non-NDD groups. There was no

significant difference in scores for NDD (M = 24.58, SD = 13.11) and non-NDD families (M = 23.01, SD = 12.92); $t(111) = -.64$, p = .521, two tailed). The magnitude of the differences in the means (mean difference = 1.57, 95% CI: -6.37 to 3.23) was very small (eta squared = .004).

Aim #2. Family Resilience and Group Membership:

Aim 2a: Overall Family Resilience. An independent samples *t*-test was conducted to compare if differences existed in ratings of overall family resilience between the NDD and non-NDD groups. There was no significant difference in scores for NDD (M = 115.76, SD = 22.79) and non-NDD families (M = 123.60, SD = 22.82); $t(111) = 1.80$, p = .07, two tailed). The magnitude of the differences in the means (mean difference = 7.84, 95% CI: -.72 to 16.40) was small (eta squared = .03).

Aim 2b: Connectedness. An independent samples *t*-test was conducted to compare if differences existed in ratings of connectedness between the NDD and non-NDD groups. There was no significant difference in scores for NDD (M = 11.30, SD = 2.55) and non-NDD families (M = 11.61, SD = 2.53); $t(111) = .59$, p = .56, two tailed). The magnitude of the differences in the means (mean difference = .31, 95% CI: -.74 to 1.35) was very small (eta squared = .003).

Aim #3. Association between Family Resilience and Pandemic Impact:

The associations between overall family resilience and pandemic impact (i.e., cumulative, indirect, and direct) were investigated using Pearson product-moment correlation coefficient (see Table 7). Preliminary analyses were performed to ensure no violation of the assumptions of normality, linearity, and homoscedasticity.

Aim 3a. Family resilience and cumulative pandemic impact. A Pearson correlation was computed to assess the linear relationship between family resilience and cumulative pandemic impact. There was not a significant relationship between the two variables, $r = -.09$, $n = 110$, $p = .350$.

Aim 3b. Connectedness and cumulative pandemic impact. A Pearson correlation was computed to assess the linear relationship between the subcategory of connectedness and cumulative pandemic impact. There was not a significant relationship between the two variables, $r = -.02$, $n = 110$, $p = .848$.

Table 7

Correlations between predictors in entire sample

Variable	1	2	3	4
1. Walsh Total	-			
2. Connectedness	.83**	-		
3. Cumulative Impacts	-.09	-.02	-	
3. Indirect Impacts	-.46**	-.36**	.68**	-
4. Direct Impacts	.06	.12	.96**	.48**

** Correlation is significant at the 0.01 level (2-tailed)

Aim 3c. Family resilience and indirect pandemic impact. A Pearson correlation evaluated the linear relationship between family resilience and indirect pandemic impact. There was a moderate, negative correlation between the two variables of family resilience and indirect pandemic impacts, $r = -.46$, $n = 113$, $p < .01$, with higher ratings of indirect pandemic impact being associated with lower family resilience, regardless of whether there was a neurodevelopmental diagnosis.

Aim 3d. Connectedness and indirect pandemic impact. A Pearson correlation was computed to assess the linear relationship between connectedness and indirect pandemic

impact. There was a moderate, negative correlation between the two variables of connectedness and indirect pandemic impacts, r = -.36, n = 113, p < .01, with higher ratings of indirect pandemic impact being associated with lower connectedness, regardless of whether there was a neurodevelopmental diagnosis (see Table 7).

Aim 3e. Group differences. Pearson correlations were computed to assess the linear relationship between group membership (NDD or non-NDD) and variables of family resilience, connectedness, and cumulative, indirect, and direct pandemic impacts (see Tables 8 and 9). When considering group differences, there was a moderate, negative correlation between the two variables of connectedness and indirect pandemic impacts, r = -.40, n = 58, p < .01, with higher ratings of indirect pandemic impact being associated with lower connectedness among non-NDD families (see Table 9), but not for the NDD families (see Table 8).

Table 8

Correlations between predictors NDD Group

Variable	1	2	3	4
1. Walsh Total	-			
2. Connectedness	.80**	-		
3. Cumulative Impacts	-.10	.02	-	
4. Indirect Impacts	-.47**	-.31	.69**	
5. Direct Impacts	.03	.10	.96**	.51**

** Correlation is significant at the 0.01 level (2-tailed)

Table 9

Correlations between predictors Non-NDD Group

Variable	1	2	3	4
1. Walsh Total	-			
2. Connectedness	.86**	-		
3. Cumulative Impacts	-.06	-.04		
4. Indirect Impacts	-.42**	-.40**	.68**	
5. Direct Impacts	.12	.14	.95**	.45**

** Correlation is significant at the 0.01 level (2-tailed)

Aim #4. Influence of Group Membership and Family Resilience and Pandemic Impact. To test the hypothesis that a neurodevelopmental disorder diagnosis may moderate the relationship between family resilience and a family's reported indirect pandemic impact, a hierarchical multiple regression analysis was conducted. In the first step, two variables were included: family resilience and diagnosis status. These variables accounted for a significant amount of variance in indirect pandemic impacts, $R^2 = .22$, $F(2, 109) = 15.11$, $p < .001$. To avoid potentially problematic multicollinearity with the interaction term, the variables were centered and an interaction term between family resilience and neurodevelopmental disorder diagnosis status was created. Next, the interaction term between family resilience and neurodevelopmental disorder diagnosis status was added to the regression model, which did not account for a significant proportion of the variance in pandemic impact, $\Delta R^2 = .0005$, $\Delta F(1, 106) = .07$, $p = .834$, $b = .000$, $t(107) = -0.005$, $p = .99$. Due to the absence of a moderating relationship between family resilience and indirect pandemic impact, an analysis of connectedness, one of the subprocesses of resilience, was deemed unnecessary.

CHAPTER 5

DISCUSSION

Introduction

While the entire world has grappled with the effects of the COVID-19 pandemic, families raising children may have been uniquely affected by the stressors of such an enduring and overwhelming event. Families raising a child with a neurodevelopmental disorder (NDD; e.g., autism spectrum disorder, attention deficit hyperactivity disorder, intellectual disability) may have been at greater risk for distress than other families, perhaps given the unique stressors brought about by their child's diagnosis and associated behaviors/needs and their child's need for specialized health services. We know that parents of children with autism, for example, are at greater risk of mental health related concerns such as stress, anxiety, and depression (Alibekova, 2022), and of particular interest is the role that family resilience may have in protecting these families as they navigated the pervasive hardships of the pandemic.

There is plenty of research demonstrating how family resilience contributes to the reduction and prevention of mental and psychological distress of family members during times of stress (Fairthorne et al., 2016). Therefore, the COVID-19 pandemic provided an opportunity to explore its impact on families, and more specifically the impact on families raising a child with an NDD. Drawing from family resilience theory and a quantitative, non-experimental study design, this study aimed to understand how the pandemic has affected families raising a child with an NDD in light of pandemic-related stressors.

The purpose of this study was to expand our understanding of the impact of the COVID-19 pandemic on families with particular focus on how families raising a child with a

neurodevelopmental disorder may be differentially impacted than families who are not. We were curious to learn more about family resilience, and specifically the connectedness aspect of family resilience, and how resilience factors may have helped families weather the stressors experienced during the first year of the COVID-19 pandemic. Next, we were interested if family resilience and connectedness were correlated with the extent that families were impacted by the pandemic. Finally, we were interested in whether the relationship between family resilience and pandemic impact was affected, or moderated, by the presence of an NDD diagnosis within the family.

Disasters and catastrophes can have both direct and indirect effects. Direct effects are those unavoidable situations that occurred due to the pandemic (e.g., job layoff) and indirect impacts are difficulties that are secondary to the direct impacts (e.g., social isolation, breakdown in relationships, increase in disruptive behaviors in children; Table 2). How the pandemic impacted families can possibly be associated with outcomes. Therefore, our first task was to differentiate potential effects, that might be considered direct versus indirect, using items from the Epidemic-Pandemic Impact Inventory-Brief. In the following paragraphs, we summarize our results and their implications.

Research Aim #1. Pandemic Impact and Group Membership. We investigated if there were differences in how the pandemic impacted (cumulative, indirect, and direct) families raising a child with an NDD compared to those who were not. Our findings did not suggest that a significant difference existed in how the pandemic impacted (cumulative, indirect, and direct) either group. There is not a one-size-fits all answer, as the impacts of the pandemic may vary depending on a range of factors such as their access to resources, support systems, and individual circumstances. However, there are several reasons why there may not have

been a significant difference in how the pandemic impacted these two groups. First, the pandemic and its associated restrictions affected everyone. The pandemic and resulting lockdowns and social distancing guidelines impacted everyone, regardless of their neurodevelopmental status. Families of all types were faced with new challenges such as disrupted routines, limited access to resources, social isolation, and increased stress and anxiety. Secondly, there was an increase in the availability of remote services. The pandemic accelerated the removal of regulatory barriers to telehealth services (Xu et al., 2022) and facilitated the adoption of remote services, such as telehealth and online therapy sessions, which could be accessed from home. This helped to ensure that families raising a child(ren) with an NDD could continue to access the support they needed, even if they were unable to attend in-person sessions. Thirdly, the pandemic increased awareness and understanding of the challenges faced by families raising a child with an NDD. This may have led to an increased focus on providing support and resources to these families, which may have helped to mitigate the impact of the pandemic.

Research Aim #2. Family Resilience and Group Membership. Next, we analyzed if there was a difference in ratings of overall family resilience between families raising a child/ren with an NDD and those raising a neurotypical child/ren. However, upon examining the data, it was found that there was no significant difference in scores of overall family resilience between the two groups despite there appearing to be a good range in scores. This suggests that even with the sometimes-reported additional challenges faced by families raising a child with an NDD, they may have developed coping strategies and resilience factors that help them overcome these challenges and function at a similar level of families raising a neurotypical child even in the face of a catastrophe.

Research Aim #3. Association between Family Resilience and Pandemic Impact. We examined whether relationships existed between overall family resilience, connectedness, and pandemic impact (cumulative, indirect, and direct). There was no significant relationship between family resilience and cumulative pandemic impact. However, there was a moderate, negative correlation between family resilience and indirect pandemic impact (r = -.46, n = 113, p < .01). Families that reported higher ratings of indirect pandemic impact also were more likely to also report lower family resilience, regardless of whether their child had a neurodevelopmental diagnosis or not. These results are consistent with published findings that show low resilience often magnifies the indirect, or secondary, impacts of an event (Lanz & Bruk-Lee, 2017). In this sample, these secondary impacts primarily manifested through an increase in household and work-related responsibilities, leading a more sedentary lifestyle, and navigating their child/ren's virtual learning.

Regarding connectedness and pandemic impacts, there was no significant correlation between connectedness and cumulative or direct pandemic impacts. However, a moderate, negative correlation did exist between connectedness and indirect pandemic impacts (r = -.36, n = 113, p < .01). These findings indicated that higher ratings of indirect pandemic impact were associated with lower connectedness for the overall sample. When considering group differences, a moderate, negative correlation existed between connectedness and indirect pandemic impacts among families who were raising a child without an NDD, but the same result was not found in families who were raising a child with an NDD. Raising a child with an NDD presents a unique set of challenges but also may present more opportunity to forge a deep connection. These families may have found ways to strengthen their confidence

in co-parenting through sharing responsibilities which may have helped them cope as well as nurture their child's emotional and physical needs (May et al., 2017).

Research Aim #4. Influence of Group Membership and Family Resilience and Pandemic Impact. Finally, we tested whether group membership (NDD or non NDD) moderated the relationship between family resilience and pandemic impact. In our sample, group membership did not moderate family resilience and pandemic impact. Perhaps this is because families reported similar levels of pandemic-related stressors. Pecor and colleagues (2021) found that quality of life decreased significantly for all parents, both those with and without a child with NDD, pre-pandemic to pandemic. Therefore, the lack of interaction found in this study may be consistent with other findings that suggest more than 60% of parents in the general population expressed an increase in stress navigating health care, distance learning, social distancing, attending to basic needs, and delayed or missed developmental milestones during the pandemic (Pecor, 2021). Another plausible conclusion may be that our lack of identification of an interaction effect is due to being underpowered to find a small effect.

Recommendations and Conclusions

Family resilience theory suggests that there are several key factors that contribute to a family's ability to pull through adversity and have a successful response to crisis. These include meaning making in adversity, having a positive outlook, spirituality, having an openness to flexibility, experiencing connectedness, and having access to social and economic resources (Walsh, 2003, 2015). The present study had several strengths including the unique time point of capturing the family perceptions of the impact of the pandemic while families were in the midst of the event itself. Data were collected between January and

July 2021, which included the end of the first wave and the entire second wave of the COVID-19 pandemic when restrictions were still in place, many schools remained shuttered, and infection rates were high (Agarwala et al., 2022). This enhanced our data collection by minimizing retrospective bias which is reliant on a person's recollection of events or experiences from the past. Retrospective bias can lead to inaccurate or incomplete data because the respondent may forget details or interpret events differently over time especially amid a stressful situation without realizing its impact.

Still, there are potential limitations to this study. First, while we had a sufficient sample size to detect medium effects in most analyses, we acknowledge that our study consisted of a relatively small sample size, which increases the risk of type II error. Little data were collected about the parent (e.g., unique stressors, mental health diagnoses), parent/child/family trauma, and specifics of relational health; therefore, this information was not available for analysis, although could have been relevant. Interviews or other reporting opportunities likely would have uncovered circumstances that were unique to the families that participated in this study. Certainly, the adage of "if you have met one person with autism, you have met one person with autism" applies here because there are innumerable individual and family dynamics that likely impacted functioning, for better or worse. Secondly, the duration of the pandemic extended beyond the point in time that our study was conducted, and our study offered a snapshot into how families were impacted in the first year of the pandemic. The toll on the physical and mental health of individuals and families will be the subject of much research for years to come as we seek to understand how families, and specifically those raising a child with an NDD, can weather prolonged stress. Parents and those with high caregiving responsibilities have demonstrated more severe and negative

responses to disasters (Russell et al., 2020) and parents of children with autism report clinically significant anxiety and depression at higher rates than parents of neurotypical children (Bitsika & Sharpley, 2013). This will be an area for longitudinal observation because though families may be adept at keeping things together during the initial stress phase while their children are young. However, over time as caregivers of children with special needs age and their child reaches adulthood, the negative impacts of chronic stress contribute to psychological strain (e.g., shame, grief, frustration, anger, and anxiety) and a decline in physical health (chronic diseases, sight problems, and hearing problems, as well as more physical pain) at higher rates than other parents (Olsen et al.,2018).

Another limitation is that mothers were the primary reporters in the current study (Table 3). Though we did not intentionally target a specific reporter during the recruitment process, our sample is underrepresented by the perspectives of other adult caregivers such as fathers, LGBT+ partners, and households that include multi-generational care providers. It is worthwhile to consider that fathers are often excluded from research studies in child psychopathology (Phares et al., 2005) even though they offer unique and important information about the child (Collins, 2021; Treutler & Epkins, 2003). Thus, future research on how families have been impacted by the pandemic will benefit by the intentional inclusion of fathers and other key caregivers because they may contribute a greater depth and more holistic context about the experiences of the family.

The primary author self-identifies as a cis-gender, White, female with specialization in working with families and children with autism but is not a direct member of the autism community; therefore, perspectives presented here are informed by the aforementioned identities, clinical connections, and lived experiences. There are limitations to studying

autism spectrum disorder if researchers are not part of the autism community. One of the most significant limitations is the potential for biases and assumptions that can influence the research process and that risk perpetuating stereotypes, or to overlook important aspects of the lived experience of raising a child with autism. We intended to focus on the protective factors of family resilience due to the largely deficit focus on this population (Denishak, 2016).

The current study gathered data primarily from a geographically centralized sample that likely had existing relationships with care providers that offered a transition to telehealth treatment resources. Participants were recruited from a developmental pediatrics clinic at an academic-affiliated medical center in the Midwest, local parenting groups on social media, postings within community-based autism providers and advocacy groups, and in a monthly ASD family support newsletter published through a local children's hospital. The COVID-19 pandemic was a worldwide phenomenon and how families dealt with adversity may be culturally or resource dependent; therefore, our findings may be most generalizable to similar populations that are likely to have access to behavioral health services in their area. There is opportunity for future studies to build upon this work and explore how family resilience may differ among other demographic characteristics particularly among racial and ethnic minority groups which were disproportionately affected by the COVID-19 pandemic and experienced a higher risk for infection, hospitalization, and death (Khanijahani et al., 2021) and were more likely to work within essential work settings where the virus risk was high (Zang et al., 2021).

Family resilience is like a muscle that can be strengthened with intentional practice. The closeness, support, warmth, or responsiveness that a family shares (Manzi & Brambilla,

2014) can be nurtured though simple pursuits that cultivate family rejuvenation. Creating time to engage in enjoyable activities together and physically interactive play has been shown to promote the relational bond between family members (Gil, 2014). Families may enjoy learning a new board game, craft, or skill together. Getting active through a sport or physical activity and friendly competition may reduce parenting stress while also promoting family bonding and improve communication (Ross et al., 2022). However, there were likely times where the increase in strict isolation may have had the opposite effect and for some families it may have brought to light underdeveloped family resilience. Marzilli and colleagues (2021) suggest that caregivers faced an increase in stress as they experienced a collision of roles and responsibilities (i.e., educator, parent, employee, childcare, partner, friend) during the pandemic. In addition to the stress, individual parental resilience has been shown to have a positive effect on family resilience (Cripe, 2013). This is important for professionals who work with families to keep in mind as the increase in conflict and stress may have compelled families to seek treatment for parental mental health concerns, family dysfunction, or management of disruptive child behaviors. Parent training programs (e.g., Parent-Child Interaction Therapy, RUBI Parent Training, Positive Parenting Program, The Incredible Years) are common skill-based therapies that focus on facilitating opportunities to promote positive interactions between parent and child and to acquire skills to help minimize conflict and build strength within the family unit. Regarding parental mental health and stress management, Acceptance and Commitment Therapy (ACT) and mindfulness based skills have been shown to be effective at ameliorating parental stress (Corbett et al., 2021). This is particularly relevant given our finding that families who experienced greater incidence

of indirect impacts were likely to have lower family resilience and may benefit from the emotion regulation effects of mindfulness (Tang, Hölzel, & Posner, 2015).

In conclusion, our study was guided by the question *why do some families adapt and flourish despite adversity and distress, while others struggle?* As we emerge from the confines of pandemic era restrictions and social, educational, and health related trends become apparent, we hope that family resilience literature will continue to expand in ways to foster and reinforce the resilience of all families. We anticipated that families raising a child with a neurodevelopmental disorder would report diminished family resilience and greater pandemic impact given their vulnerability to added stress, but our findings did not show evidence of a difference between the two groups of families. Emerging research suggests that the halt to a busy lifestyle was a welcome change and offered some families the opportunity to discover and nurture new abilities in their child with ASD (Tokatly Latzer et al., 2021). While families raising a child with an NDD bear an immense load of responsibility, their experience with their child's abilities may have also been a protective factor for them as they entered pandemic-related interruptions. Perhaps, the impact of the pandemic may have been a secondary concern to the general management and navigation of their child's diagnosis (e.g., impairments in communication, restricted, repetitive, or disruptive behaviors, medical needs). The complexities of their child's diagnosis may have overshadowed or lessened the perceptions of difficulty of the pandemic. Indeed, we have much to learn from these families about how to support and build family resilience and well-being in the face of life's storms.

APPENDIX

Caregiver Demographics

1. Which option best describes your marital status?
    a. Never married
    b. Married, or in a domestic partnership
    c. Widowed
    d. Divorced
    e. Separated

2. Which option best describes your sexual orientation
    a. Straight/Heterosexual
    b. Lesbian
    c. Gay
    d. Bisexual
    e. Not listed (please specify) _____

3. Are you of Hispanic, Latino, or of Spanish origin?
    a. Yes
    b. No

4. Which option(s) best describe your race?
    a. Asian
    b. African American / black
    c. American Indian / Alaskan Native
    d. Middle Eastern
    e. Native Hawaiian /Pacific Islander
    f. White

5. To which gender do you most identify?
    a. Female
    b. Male
    c. Transgender female
    d. Transgender male
    e. Gender non-conforming
    f. Not listed (please specify) _____
    g. Prefer not to answer

6. What category best includes your age?
    a. 18-20
    b. 21-29
    c. 30-39
    d. 40-49
    e. 50-59
    f. 60 or older

7. How many adults over the age of 18 live in your home?
    a. 1
    b. 2
    c. 3
    d. 4
    e. More than 4

8. How many children younger than 18 are living in your home?
    a. 1
    b. 2
    c. 3
    d. 4
    e. 5
    f. More than 5 (please specify) _____

9. If other children are part of your family and living with you in your home, what are their ages?
    a. _____
    b. _____
    c. _____
    d. _____
    e. _____

10. What is your estimated household Income
    a. $0 – $9,999
    b. $10,000 – $19,999
    c. $20,000 – $29,999
    d. $30,000 – $39,999
    e. $40,000 – $49,999
    f. $50,000 – $59,999
    g. $60,000 – $69,999
    h. $70,000 – $79,999
    i. $80,000 – $89,999
    j. $90,000 – $99,999
    k. $100,000 or more

11. Does your child/children receive free and reduced lunch at school?
    a. Yes
    b. No

12. Is your child/children currently covered by one of the following health insurance or health coverage plans?
    a. Insurance through a current caregiver employer
    b. Medicaid, Medical Assistance, or any kind of government-assistance plan

c. TRICARE or other military health care
d. Indian Health Service
e. Any other type of health insurance or health coverage plan (specify) _____
f. No insurance/Uninsured

13. Please tell us about your housing
a. We Rent our home or apartment
b. We own our home

Epidemic-Pandemic Impacts Inventory (EPII)
-Brief Form

INSTRUCTIONS

We would like to learn how COVID-1o9 has changed people's lives. For each statement below, please indicate whether the pandemic has impacted you or your family in the way described.

Since the COVID-19 pandemic began, what has changed for your or your family?					
1. I or someone in my home was laid off, furloughed, had to close a business, or had reduced work hours	0 Did not happen	1 Happened but no impact on me or my family	2 Some impact on me or my family	3 A lot of impact on me or my family	4 Extreme impact on me or my family
2. I lor someone in my home had to work in close contact with people who might be infected	0 Did not happen	1 Happened but no impact on me or my family	2 Some impact on me or my family	3 A lot of impact on me or my family	4 Extreme impact on me or my family
3. I or someone in my home had an increase in workload or work responsibilities	0 Did not happen	1 Happened but no impact on me or my family	2 Some impact on me or my family	3 A lot of impact on me or my family	4 Extreme impact on me or my family
4. I or someone in my home provided direct care or services to people who had the disease	0 Did not happen	1 Happened but no impact on me or my family	2 Some impact on me or my family	3 A lot of impact on me or my family	4 Extreme impact on me or my family
5. A child or teenager/young adult I care for could not go to school or needed home instruction	0 Did not happen	1 Happened but no impact on me or my family	2 Some impact on me or my family	3 A lot of impact on me or my family	4 Extreme impact on me or my family
6. Childcare or babysitting was unavailable to me or someone in my home when needed	0 Did not happen	1 Happened but no impact on me or my family	2 Some impact on me or my family	3 A lot of impact on me or my family	4 Extreme impact on me or my family

7. I or another caregiver had more conflict with or was harsher in disciplining my child or children	0 Did not happen	1 Happened but no impact on me or my family	2 Some impact on me or my family	3 A lot of impact on me or my family	4 Extreme impact on me or my family
8. I spent a lot more time taking care of a family member most days	0 Did not happen	1 Happened but no impact on me or my family	2 Some impact on me or my family	3 A lot of impact on me or my family	4 Extreme impact on me or my family
9. My family had to move, relocate, was evicted, or became homeless	0 Did not happen	1 Happened but no impact on me or my family	2 Some impact on me or my family	3 A lot of impact on me or my family	4 Extreme impact on me or my family
10. There was an increase in verbal or physical conflict with a partner or spouse	0 Did not happen	1 Happened but no impact on me or my family	2 Some impact on me or my family	3 A lot of impact on me or my family	4 Extreme impact on me or my family
11. There was an increase in verbal or physical conflict among other family in my home	0 Did not happen	1 Happened but no impact on me or my family	2 Some impact on me or my family	3 A lot of impact on me or my family	4 Extreme impact on me or my family
12. My family was unable to pay for or get enough food or clean water	0 Did not happen	1 Happened but no impact on me or my family	2 Some impact on me or my family	3 A lot of impact on me or my family	4 Extreme impact on me or my family
13. My family was unable to pay important large bills like rent or utilities	0 Did not happen	1 Happened but no impact on me or my family	2 Some impact on me or my family	3 A lot of impact on me or my family	4 Extreme impact on me or my family
14. My family had trouble getting places due to less access to public	0 Did not happen	1 Happened but no impact on	2 Some impact on	3 A lot of impact on	4 Extreme impact on

transportation or concerns about safety		me or my family	me or my family	me or my family	me or my family
15. I or someone in my home did not have the ability or resources to talk to or see family or friends while separated	0 Did not happen	1 Happened but no impact on me or my family	2 Some impact on me or my family	3 A lot of impact on me or my family	4 Extreme impact on me or my family
16. My family had to cancel or could not attend important celebrations (such as weddings) or religious ceremonies or funerals	0 Did not happen	1 Happened but no impact on me or my family	2 Some impact on me or my family	3 A lot of impact on me or my family	4 Extreme impact on me or my family
17. I or someone in my home was unable to be with a close family member who was hospitalized, in a nursing home, or in critical condition	0 Did not happen	1 Happened but no impact on me or my family	2 Some impact on me or my family	3 A lot of impact on me or my family	4 Extreme impact on me or my family
18. I or someone in my home was isolated or quarantined due to possible exposure to the disease, symptoms, or increased risk	0 Did not happen	1 Happened but no impact on me or my family	2 Some impact on me or my family	3 A lot of impact on me or my family	4 Extreme impact on me or my family
19. I had limited physical closeness with my child or loved one due to concerns of infection	0 Did not happen	1 Happened but no impact on me or my family	2 Some impact on me or my family	3 A lot of impact on me or my family	4 Extreme impact on me or my family
20. My child[ren] had more frequent or severe behavioral or emotional problems (for example, mood, anxiety, sleep, nightmares)	0 Did not happen	1 Happened but no impact on me or my family	2 Some impact on me or my family	3 A lot of impact on me or my family	4 Extreme impact on me or my family
21. I or someone in my home had more frequent or severe mental health problems, sleep, or use of alcohol or substances	0 Did not happen	1 Happened but no impact on me or my family	2 Some impact on me or my family	3 A lot of impact on me or my family	4 Extreme impact on me or my family

22. I or someone in my home was unable to access or was less satisfied with mental health treatment or therapy	0 Did not happen	1 Happened but no impact on me or my family	2 Some impact on me or my family	3 A lot of impact on me or my family	4 Extreme impact on me or my family
23. I or someone in my home could not get enough medication or medical treatment for a chronic illness or pain	0 Did not happen	1 Happened but no impact on me or my family	2 Some impact on me or my family	3 A lot of impact on me or my family	4 Extreme impact on me or my family
24. I or someone in my home got less exercise, spent more time sitting down, or ate more junk food	0 Did not happen	1 Happened but no impact on me or my family	2 Some impact on me or my family	3 A lot of impact on me or my family	4 Extreme impact on me or my family
25. I or someone in my home had important medical procedures cancelled or was unable to access medical care for a serious condition	0 Did not happen	1 Happened but no impact on me or my family	2 Some impact on me or my family	3 A lot of impact on me or my family	4 Extreme impact on me or my family
26. I or someone in my home tested positive for COVID-19 and had severe symptoms	0 Did not happen	1 Happened but no impact on me or my family	2 Some impact on me or my family	3 A lot of impact on me or my family	4 Extreme impact on me or my family
27. A close friend or family member died from COVID-19 or related complications	0 Did not happen	1 Happened but no impact on me or my family	2 Some impact on me or my family	3 A lot of impact on me or my family	4 Extreme impact on me or my family
28. My family enjoyed more quality time together, paid more attention to personal health, or made new connections with one another or with friends	0 Did not happen	1 Happened but no impact on me or my family	2 Some impact on me or my family	3 A lot of impact on me or my family	4 Extreme impact on me or my family
29. I or someone in my home was harassed or blamed for causing or spreading	0 Did not happen	1 Happened but no	2 Some impact on	3 A lot of impact on	4 Extreme impact on

COVID-19, or was denied or unable to access services or treatment for COVID-19 because of my race/ethnicity		impact on me or my family	me or my family	me or my family	me or my family
30. I found greater meaning and was more effective in my work, school, or friendships than before COVID-19	0 Did not happen	1 Happened but no impact on me or my family	2 Some impact on me or my family	3 A lot of impact on me or my family	4 Extreme impact on me or my family

Walsh Family Resilience Questionnaire

Directions: We are interested in your family's experience with your highly stressful situation. Please share your view on how your family deals with crises and ongoing challenges. Read each statement below and click a number, 1-5, to indicate how much this is true for your family.

Rarely/Never (1), Not often (2); Sometimes (3); Often (4); Almost Always (5)

1. Our family faces difficulties together as a team, rather than individually.
2. We view distress with our situation as common, understandable.
3. We approach a crisis as a challenge we can manage and master with shared efforts.
4. We try to make sense of stressful situations and focus on our options.
5. We keep hopeful and confident that we will overcome difficulties.
6. We encourage each other and build on our strengths.
7. We seize opportunities, take actions, and persist in our efforts.
8. We focus on possibilities and try to accept what we can't change.
9. We share important values and life purposes that help us rise above difficulties.
10. We draw on spiritual resources (religious or nonreligious) to help us cope well.
11. Our challenges inspire creativity, more meaningful priorities, and stronger bonds.
12. Our hardship has increased our compassion and desire to help others.
13. We believe we can learn and become stronger from our challenges.
14. We are flexible in adapting to new challenges.
15. We provide stability and reliability to buffer stresses for family members.
16. Strong leadership by parents/caregivers provides warm nurturing, guidance, and security.
17. We can count on family members to help each other in difficulty.
18. Our family respects our individual needs and differences.
19. In our immediate and extended family, we have positive role models and mentors.
20. We can rely on the support of friends and our community.
21. We have economic security to be able to get through hard times.
22. We can access community resources to help our family through difficult times.
23. We try to clarify information about our stressful situation and our options.
24. In our family, we are clear and consistent in what we say and do.

25. We can express our opinions and be truthful with each other.
26. We can share difficult negative feelings (e.g., sadness, anger, fears).
27. We show each other understanding and avoid blame.
28. We can share positive feelings, appreciation, humor, and fun and find relief from difficulties.
29. We collaborate in discussing and making decisions, and we handle disagreements fairly.
30. We focus on our goals and take steps to reach them.
31. We celebrate successes and learn from mistakes.
32. We plan and prepare for the future and try to prevent crises.

What family beliefs and/or practices are especially helpful in dealing with your stressful situation?

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VITA

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As an undergraduate research assistant, Jen became interested in helping families who have been affected by trauma and adversity as well as implementation research and building community-based partnerships. This provided an opportunity to join the clinical psychology doctoral program at University of Missouri-Kansas City in 2017. In addition to her academic and research pursuits, Jen worked with an early childhood education program and counseling center that serves children and their families as they recover from difficult life experiences. She completed her pre-doctoral psychology internship with specific training in neuro and autism assessment at Pine Rest Christian Mental Health Services in Grand Rapids, Michigan. She received her PhD in clinical psychology in 2023.

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