

Experiences of Family Enmeshment and Emotional Autonomy Among Adolescents Caring for Siblings with Autism

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ABSTRACT

Family caregiving affects many families in the United States, including new parents, adult children caring for elders, and family members caring for relatives with temporary or permanent healthcare needs. While previous studies have focused on various aspects of caregiving, little research attention focuses on adolescent caregivers. The role of caregivers within a family may include assistance with daily tasks such as bathing, dressing, feeding, and medication management, and some tasks and expected time commitments may be inappropriate for adolescents and hinder their socio-emotional development. When care recipients have a condition that requires an elevated level of care, such as autism spectrum disorder, the burden on adolescent caregivers may be exacerbated. Guided by Family Systems Theory, this study explores how the emotional boundaries of adolescent caregivers are affected when their sibling has been clinically diagnosed with autism. Potential participants were identified through social networks and interviewed in a semi-structured interview. Findings show that emotional boundaries were affected by the themes of individual actions and family support, partially aligning with our hypothesis that emotional autonomy and self-efficacy could impact caregivers' emotional boundaries. Findings suggest that support-based intervention and public policies may mitigate enmeshed behaviors in families and relieve the caregiving burden for adolescents. Further research should aim to identify specific interventions and supports for adolescent caregivers, establishing appropriate boundaries around their caregiving tasks, meeting societal expectations by completing school, and providing support for longer-term personal goals, such as a career and family.

KEYWORDS: Caregivers, adolescents, parentification, cohesion, enmeshment

Literature Review

Cultural Context of Caregiving in the United States

The gendered expectations of family caregiving are well established, both in the United States (U.S.) (Calarco, 2020) and in other countries (Bainbridge et al., 2021). Individuals who

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identify as female typically report higher levels of caregiving burden compared with individuals who identify as male (Nakamura & Akiyoshi, 2015). Although in recent decades, men and fathers have marginally increased caregiving activities (Martinez, 2016; Rankin, 2019), it is still generally assumed, both by caregivers and others, that women take on the role of the caregiver within a family (Mackie et. al., 2022).

While the gender identity of a caregiver has been noted in many studies, the age of caregivers typically receives less attention. Young children are often cared for by their (young) adult parents or other forms of childcare, such as paid professionals or unpaid relatives (Laughlin, 2013; Park & Pena, 2021). Older adults who are declining or have a disability may be cared for by their middle-aged children or pay for professional adult caregivers. Previous studies focusing on caregiver populations have looked at the trade-offs made by working-age adults, primarily focusing on lost wages as a result of time spent on caregiving and other economic measures (Bainbridge et al., 2021; Schofield et. al., 2019). However, few studies focus on the “hidden” population of caregivers who are adolescents, aged 12 to 19 years old. Adolescents typically are not in the workforce full time, so it is a challenge to find a meaningful measure to understand the impact of caregiving in terms of a trade-off between time spent on caregiving activities and time spent doing non-caregiving activities (homework, school tasks, extracurriculars).

Understanding the experiences of caregivers is important because the need for caregiving within families is so widespread. Approximately 43 million Americans have provided unpaid caregiving to an adult or child, with about 34 million caring for an adult older than age 50. Additionally, about 40 million Americans have provided unpaid caregiving for an adult with an illness or disability (Family Caregiver Alliance, 2023). Further, about 20% of U.S. families have a child with a special health care need or children who “have or are at increased risk for chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally (Maternal and Child Health Bureau, 2022, p. 1). Some special needs, such as mild asthma, can eventually be managed independently as a child grows up. However, other special needs, such as severe autism, will require life-long caregiving. The responsibility of providing and/or managing the caregiving tasks needed for an individual often falls to family members, who, more likely than not, do not have formal training in caregiving or health care (Boyle, 2017).

Sources of Support for Caregivers in the United States

There are a few sources of support outside the family for families with a child who needs caregiving. Those with financial resources may outsource caregiving tasks (e.g., direct care of the child) or other household tasks (e.g., cooking, cleaning, laundry) so that they themselves may provide direct care. Additionally, there may be public services available. Head Start reserves 10% of enrollment for children with special healthcare needs (U.S. Department of Health and Human Services, 2024). Some communities in the U.S. have regional centers, which can provide support for parents who have a child with special health care needs by connecting the family to resources (Family Resource Centers Network of California, 2022). As children grow up, public schools provide some services in the form of Individualized Education Plans (IEPs).

In theory, support from public programs could reduce the need for parents to rely on relatives, including their children, to provide the additional care needed for a child with special health care needs. However, in practice, the variety of qualification criteria combined with the rapid growth and change inherent in children can result in confusion about eligibility (Daly & Lewis, 2000).

Family Systems Theory

Given the paucity of consistent public systems of support for caregiving families in the U.S., this work broadly assumes that the majority of families provide all or most day-to-day caregiving within the resources available, such as the time and labor of friends and family, including other children. Thus, this research utilizes the Family Systems Theory to understand the role of adolescent caregivers within their family systems. The three main components of a family system are elements (the members of a family), interconnections (the information shared within a family), and function (how members of a family take care of each other) (Watson, 2012). In the context of this study, parents are the element, interconnections are how they share emotional burden/information, and function is the child's role in a typically developing family versus a normal one (Watson, 2012).

Caregiving in Families with a Child with Autism

While caregiving experiences have been explored broadly, few studies seek to understand the experiences of typically-developing adolescents who provide caregiving for siblings or other family members with neurodevelopmental disorders (NDDs). In particular, few studies have addressed the experience of adolescents caring for siblings or family members with autism spectrum disorder (ASD).

ASD is an NDD that affects many aspects of an individual's daily life, and the effects may be more or less severe depending on the individual. Some individuals with autism may struggle slightly with communication and social cues, but may otherwise be considered high functioning and not require much, if any, caregiving across the life course (National Institute of Neurological Disorders and Stroke, 2023). However, individuals with more severe effects require lifelong caregiving in areas such as bathing, dressing, feeding, transportation, communication, and medication administration. Thus, existing research focuses on improving the quality of life for autistic individuals (Boyle et al., 2011). One way to enhance the quality of life for ASD individuals is to maintain a sibling bond because it is one of the longest familial bonds for many people (Stoneman, 2001). However, families with a child with ASD report a lower level of family functioning (Baker et al., 2011), and the framework of the family systems theory explains how an increased reliance on children to sustain their sibling emotionally can interfere with the system's interconnectedness or purpose (Watson, 2012) with both positive (Stoneman, 2001) or negative impacts on familial environments (Baker et al., 2011). When parents take a more active caregiving role, siblings are less likely to be parentified and can have a common sibling bond that promotes healthy familial relationships (Gundersen, 2012).

Sibling Dyads

Parentification commonly occurs within sibling dyads (Young & Flannigan, 2021). Additionally, family members have taken responsibility when a member gets diagnosed with an illness later in their lives, as seen with cases of dementia (Sperling et al., 2020) and acquired brain injury (Degeneffe, 2015). These responsibilities include taking care of their siblings and parents (Petrowski & Stein, 2016) and fall under emotional and instrumental parentification (Hooper, 2008). However, existing studies often use quantitative or observation-based methods such as answering a questionnaire with scales (Laghi, 2018), surveys or survey packets (Degeneffe, 2015; Mostafa et al., 2018), and interventions and scales (De Stefano et al., 2022). Furthermore,

adolescents are typically a hard-to-reach population, and survey response rates are likely to be low among individuals aged 11-19.

Parentification of Adolescent Caregivers

In some cases, families with a child with special health care needs may delegate caregiving tasks to adolescent carers. Hamilton and Adamson (2013) define adolescent carers as “people twenty-five and younger who provide substantial unpaid support to a family member with chronic illness, disability, or mental health concern” (Hamilton and Adamson, 2013, p. 101). Within a family system, hidden care may occur in the form of parentification. Hooper (2008) defines parentification as “children [taking] on roles and responsibilities usually reserved for adults,” and many enmeshed family dyads, or family groups, exhibit high degrees of parentification (Hooper, 2008, p. 1). Categorizing parentification as instrumental or emotional allows literature to describe a child’s role as a figure involved with household responsibilities (i.e., food preparation and finances) or familial support (i.e., parents confiding in their child and establishing familial harmony) (Dariotis et al., 2023). Parentified behavior may also create a reinforcing feedback loop between a parent and child, as the child may seek validation or recognition from their parents based on their ability to complete household tasks (Watson, 2012).

As a result of parentification, some children cannot appropriately mature through Erikson’s eight stages of psychosocial development, which poses a risk to developing children (Borchet et al., 2018). Arnett and Erikson also explain that parentified children cannot establish their identity because they can prematurely commit to ideals set by their parents (Arnett, 2000; Erikson, 1963). The lack of progression prevents children from handling certain social situations and causes emotional distress. Erikson (1963) states that the experience of being parentified as a child can continue to impact their lives until adulthood and after leaving their family home.

Although there are some positive familial experiences in caregiving when tasks are age-appropriate, parentification occurs when tasks exceed a child’s capabilities (Saha, 2016). When caretakers compromise their health to provide care in cases like extreme parentification, they risk exacerbating previously existing health concerns and internalized concerns about caregiving (Daly & Lewis, 2000; De Stefano, et al., 2022; Meier et al., 2014). In extreme cases of parentification, caregivers experience varied (negative and positive) life satisfaction and trait anxiety (Çimşir & Akdoğan, 2021). Çimşir and Akdoğan (2021) defined life satisfaction as “an individual’s satisfaction with their life,” in accordance with Diener et al.’s (1985) Satisfaction With Life Scale (SWLS) and defined trait anxiety as an individual tendency to approach dangerous or threatening situations (Çimşir & Akdoğan, 2021, p. 106). Furthermore, extreme parentification poses a threat to adolescent caregivers’ mental health because they may not be able to articulate their needs and do not have access to adults in their lives who can support their mental needs and cannot speak about personal concerns like mental health (Borchet et al., 2018; Hooper, 2008).

Emotional Autonomy, Self-efficacy, and Support Systems

Defined as individuals expressing initiative in relationships with others (Hauser et al., 1991; White, 1989), emotional autonomy plays a role in most social interactions—namely parents and other agents of early social development (Hauser et al., 1991; Seligman & Peterson, 1986; White, 1989). However, Barber et al. (1994) and Buehler and Watt (1992) explained that individuals lacking emotional autonomy would remove themselves from social interactions, which is a behavior that emerges from childhood experiences and may hinder the emotional maturity of a child (Borchet et al., 2018). Furthermore, self-efficacy is defined as a person’s belief that they are

capable of accomplishing a specific task or achieving a goal (Bandura, 1997). In the context of caretaking, Au (2009) identified self-efficacy as an individual belief in handling caregiving problems. When caretakers receive support from a support system, they are likely to resolve risks and problems more effectively (Krause, 2003). De Stefano et al. (2022) similarly showed that a support system was beneficial in reducing caregiver burden. A support system includes reaching out to friends, family, and intervention, which can encourage fewer depressive symptoms in caregivers (Au, 2009; De Stefano et al., 2022).

Method

Study Rationale

Although there have been studies conducted on sibling dyads with an ASD sibling and a typically developing sibling (TDS), these studies prioritize quantitative methods of sampling and analysis, such as email advertisements and surveys (Nuttall et al., 2018; Tomeny et al., 2017) or conducting a content analysis (Tomeny & Barry, 2013). Existing literature has examined caregiving and parentification in neurotypical sibling relationships, but research on caregivers and their autistic siblings is minimal (Nuttall et al., 2018; Tomeny & Barry, 2013; Tomeny et al., 2017). Additionally, as child caregivers grow older, they become more mature and capable of providing more complex caregiving tasks (e.g., driving to medical appointments and de-escalating emotional distress). Therefore, this paper will address the research question: How does caregiving for siblings on the autism spectrum affect the emotional boundaries of adolescent caregivers? In accordance with previous research findings, we hypothesize that caregivers will experience a lack of emotional autonomy (Au, 2009) but display a high degree of self-efficacy (Barber & Buehler, 1996).

Study Design

This qualitative study proceeded in two stages. First, participants were recruited via CRV's social connections at their institution. Once potential participants were identified, a set of screening questions was administered to make sure participants met the study criteria. Interview questions were developed based on previously validated scales, and participants were interviewed using a semi-structured interview process. Finally, data were analyzed using a constant comparative approach. Throughout the data collection process, steps were taken to ensure participant safety and avoid potentially triggering and distressing experiences.

Participant Recruitment

Participants were recruited through the first author's (CRV) social connections using snowball sampling. Snowball sampling encourages participation because there is a relationship between the participant and the person they suggested (Miles et al., 2018). Initially, two prospective participants were gathered by advertising the study in CRV's classes at their institution. The first two prospective participants did not partake in the interview because one person did not respond to communications, and the other did not meet the criteria for the study. CRV consequently adjusted the recruiting method and asked institution staff to utilize their social connections to identify possible participants. All participants were recruited through the revised approach. Three participants were recruited directly from CRV's school, while two came from staff connections. Then, the first group of participants was asked to reach out to anyone who may fit the study's criteria (see Table 1 for participant demographics).

This procedure was necessary to find participants because of the criteria's small, narrow, and sensitive nature. The criteria are sensitive because studies explain that participants may feel anxiety or depression when providing caregiving for a family member. Using a sampling method that reaches a broad audience (such as sending a survey in a mass email) can be unnecessarily triggering and thus inappropriate. The process also identifies hidden populations, which are “hidden” because “no sampling frame exists and public acknowledgment of membership in the population is threatening” (Heckathorn, 1997, p. 174).

Screening Questionnaire

To ensure participants met study requirements, they were given a screening questionnaire. Questions on the screening survey were: (1) Do you have one or more siblings? (2) Is your sibling clinically diagnosed with Autism Spectrum Disorder? (3) Do you currently provide care for your autistic sibling? After participants completed a consent form, they received a survey. The survey was an additional measure to verify participants’ adherence to the study criteria. If a sibling is not clinically diagnosed with autism by a medical professional, the overall research may be compromised because they do not fit the population criteria (Stansfield et al., 2014).

Interview Question Development

The interview questions were created and modified from previous scales Preliminary questions were used to establish the role of emotional boundaries in caregivers’ lives. These questions are modeled on Petrowski and Stein’s (2016) study (daughters approaching their mother’s mental illness), which invited participants to speak about specific topics. Petrowski and Stein’s (2016) topics included an explanation of maternal mental illness, the relationship with the mother, delegation of caretaking roles in the family, “possible feelings of obligation towards the mother,” relationship with other immediate family members, and “the perceived impact of their mothers on their own lives” (Petrowski and Stein, 2016, p. 2876).

The main questions of the interview are modified from verified scales. The first scale is FACES IV, which measures a healthy level of family cohesion and enmeshment (Olson et al., 2006). Family cohesion is defined as support and care between family members (Barbarin & Tirado, 1984; Moos, 1974), whereas enmeshment is a pattern of behaviors that encourage psychological and emotional fusion within families (Barbarin & Tirado, 1984; Barber et al., 1994; Greenberger & Sørensen, 1974). FACES IV measures emotional boundaries and distress because prior research has shown that high degrees of enmeshment and cohesion can cause excess stress to caregivers (De Stefano et al., 2022). The original scale uses a 5-point Likert scale to determine family enmeshment and cohesion. An example can be seen in one original question, "Family members are supportive of each other during difficult times." In this study, the question was modified to “In your family, are family members supportive of each other during difficult times?” to establish rapport and make the question applicable to an interview setting.

The second scale, a self-efficacy scale, allows for the analysis of participants’ perceived self-efficacy and their confidence in handling a caregiving situation (Steffen et al., 2002). The original scale was answered on a 0-100 scale, where 50% meant that a caregiver could perform an action with a 50-50 chance if they gave their best effort. A sample question from the scale was “How confident are you that you can ask a friend/family member to stay with [care recipient] for a day when you have errands to be done?” and was modified to be “Think back to a time when you had an errand to run and you had to take care of your sibling... Can you tell me about that experience?” to coincide with probe-based questioning strategies.

The final scale used to develop interview questions, Instrumental Activities of Daily Living (IADL), measures the degree of care needed and is a basis for comparing what caregivers may experience (Lawton & Brody, 1969). Giving participants a question that standardizes their experiences allows analysis to compare the similarities and differences between each participant. These questions, used initially to diagnose clients by coding their data based on a numerical response, were modified to be open-ended questions. For example, a statement on IADL talks about a client's ability to prepare food. The modified question, "How would you describe the behavior of your sibling with ASD in day-to-day life?" achieves the same goal of finding different life behaviors in ASD siblings. Appropriate probes were used, and rapport was built with participants by describing CRV's personal experiences to clarify questions. Although each interview was conducted under a limited time frame (ranging from twenty to thirty minutes), standard probes were used to gain answers that may apply to other scale questions. An example of a typical probe included "Can you give me an example?".

Interview Procedures

Participants who met the requirements were contacted via email, text, or social media messaging to schedule a semi-structured interview. All interviews were conducted under the supervision of CRV's mentor. Participants who were unable to meet in person were interviewed over Zoom; however, local participants were interviewed in person due to the added convenience. Before each interview, participants were reminded of the study's goal and informed that their consent was voluntary and could be rescinded at any time. Participants were required to confirm their verbal consent to participate in the study.

After the interview, participants were given a list of counseling services they could contact if needed. Over Zoom, participants received these resources via chat alongside a brief verbal explanation of the resources. Participants who attended the researcher's institution were also given counseling services at the end of each interview, and they were referred to the school psychiatric social worker. They were also given resources via their preferred methods of communication (texting, emailing, or social media messaging). Each interview was transcribed verbatim for emergent codes using thematic data analysis to determine the effects of caregiving on participants' emotional autonomy (Petrowski & Stein, 2016).

The study adopted a semi-structured interview format from Petrowski and Stein (2016). Although their research focused on mother-daughter relationships, they used interviews to explore in-depth perspectives on caregiving relationships and family dynamics. The flexible structure of semi-structured interviews ensured that participants spent less time dwelling on potentially triggering and distressing memories. After collecting data, thematic analysis via emergent codes was used to find trends in participant responses. Similarly, this study also uses semi-structured interviews with thematic analysis.

Informed Consent

Once consent documents and all research instruments were developed and compiled, they were submitted to a panel at CRV's home institution. The review panel included academic administrators, instructors, a psychiatric social worker, and research mentors. Because this study worked with adolescents, two versions of the consent form were required—one for the adolescent participant and one for their guardian. Guardian consent forms included the purpose of the study and what their child would be asked to do. Establishing clear parameters remained essential because of the study's sensitive nature, and guardians were informed that their permission could

be revoked at any time. The consent form also established that any possible child abuse or neglect would be reported because a mandated reporter monitored the study. Participant consent forms entailed the same information, with the exception of needing their contact information for further contact about their eligibility.

Participants were then identified and given consent forms before further participation. Consent forms were emailed or handed to participants after expressing interest. Waiting for referrals was appropriate because participants needed to be comfortable participating in the study. Five individuals signed consent forms. The five participants were anonymized by assigning them a number from a random number generator (numbers 1-5). Consent forms were distributed physically when possible to participants and, when appropriate, their parent/guardian. However, one individual unable to collect a physical copy of the form uploaded a picture of their signature, which was later printed out. Adult participants signed the consent form electronically and delivered it via email. Both consent forms stated that participants could withdraw at any time without penalty to ensure their comfort with participating.

Post-Hoc Permission to Publish

Participants were contacted after the study through their preferred method of communication (email, text, or social network messages) because the study's initial consent forms did not cover the use of participant data outside of CRV's institution. After giving each participant the chance to ask questions, all five participants gave their post-hoc permission to publish results.

Analysis

This study used a form of thematic data analysis known as emergent coding, which Braun and Clarke (2006) define as codes developing as the study progresses. A hierarchical structure was applied to interview transcripts, with themes covering broader concepts and codes nested within themes. However, the definitions of four of the six emergent codes were modified from their original meanings in the caregiving literature to more precisely assess the emotional boundaries of adolescent caregivers. The rigor of the data collected was ensured by using a constant comparison approach to build the thematic structure as each interview was added to the data set. Additionally, the first author maintained a reflexive journal throughout the research process, ensuring the self-awareness and authenticity that are critical to rigorous qualitative analysis (Tracy, 2010).

Positionality

First Author. The analysis was framed by the authors' positionality, primarily the first author, CRV. Until recently, CRV was an adolescent caregiver for their older sibling, who was diagnosed with ASD at age 4, when CRV was age 1. CRV's sibling qualifies as dependent based on the IADL in all subsections. Thus, CRV provided age-appropriate caregiving for their sibling from an early age, including general housekeeping tasks like washing dishes and bedmaking to maintain general cleanliness, preparing balanced meals, and doing all of their sibling's personal laundry (sections C, D, and E). As CRV became able to take on more responsibilities, they took on tasks like accompanying her sibling in public and private transportation (section F), making calls for her sibling (Section A), and assisting in medication administration (section G). CRV's caregiving experiences also encompass tasks not listed on the IADL, such as assistance with personal hygiene (bathing and dressing) and monitoring their sibling's safety.

CRV's feelings towards caregiving also changed during the study. During the study, CRV was able to share more about their caregiving situation and connect to adequate support systems within her institution. As they gained greater insight into their own experiences, they grew comfortable speaking openly with teachers and mentors. These positive connections and additional support resources helped CRV to ultimately understand and accept their caregiving experiences and assisted CRV in a truthful articulation of each participant's experiences.

Second Author. The second author, JFM, has focused her research on caregiving, specifically for young children aged birth to 5, for many years. Recently, she completed a study of how caregiving may interrupt the educational trajectories of individuals and how those interruptions are managed in families, through the lens of reproductive labor and opportunity cost. This work broadened her focus from caregiving for young children to family caregiving more generally.

JFM is also interested in individual and collectivist cultural expectations in families, viewing the adolescent caregiver phenomenon as an example of collectivist expectations. Her perspective is that in the U.S., collectivist expectations may lead to friction within a broader society that values individual achievements, such as college completion, employment, and financial independence, against expectations to provide unpaid care within a family.

We acknowledge that CRV's unique experiences as a sibling caregiver framed the analysis, particularly regarding the sibling dyad concept and circular causality, because CRV could understand interview transcripts individually and differentiate the possible impacts of autistic sibling dyads compared to TDS dyads, as autism is a life-long disorder and caregiving responsibilities remain consistent whereas TDS can "age out" of dependent behaviors. However, to avoid leading participants to a specific answer, CRV worked with their institution's psychiatric social workers, student mentors, and the second author to create a set of questions that would be both neutral and allow for meaningful responses.

Results

Five individuals participated in the interviews, including three adolescents and two adults who were caregivers for a sibling when they were adolescents (Table 1). Findings include two themes and six codes.

Table 1
Demographics of Caregivers and their Siblings.

Participant	Participant approximate age	Sibling age
1	Adolescent	12 years old
2	Adult	26 years old
3	Adult	26 years old
4	Adolescent	11 years old
5	Adolescent	8 years old

Two themes and six codes emerged from the data (Table 2). Four codes fit within the two themes, and two additional codes were narrow in scope but did not fit within a theme, so they were stand-alone codes. The codes are summarized in Table 2.

Table 2
Themes, Codes, and Definitions

Theme	Codes	Definition
Individual action	Emotional autonomy	Individuals express initiative in relationships with others.
	Self-efficacy	An individual believes they can adequately handle caregiving problems.
	Cohesion	Healthy support between family members.
Family support	Enmeshment	Unhealthy emotional/psychological family fusion
No theme	Emotional impact	Perception of care experience.
	Sibling independence	Activities of daily life that siblings can conduct.

Individual Action

As observed during the coding process, individual action was a common theme in participant responses. Two codes resulted from the theme: *emotional autonomy* and *self-efficacy*. Codes that included any time a participant had to act individually to respond to their caregiving circumstances were categorized under individual action.

Emotional Autonomy

Emotional autonomy was used as a code to measure the emotional boundaries that participants had established in their relationships. Responses were coded as emotionally autonomous when participants displayed active help-seeking behavior or took the initiative to provide help in relationships and/or emotions. Each response demonstrated either high emotional autonomy (when participants displayed active help-seeking behavior or showed initiative to provide help in relationships) or low emotional autonomy (participants did not display active help-seeking behaviors or initiative in relationships).

Factors that heavily influenced *emotional autonomy* were *family cohesion* and *family enmeshment*. Four out of five participants demonstrated *family cohesion* and *low emotional autonomy*. These codes are viewed in parallel because participants from a cohesive environment receive healthy support from their families (being available to talk to each other and checking in on their emotional and mental state). This means they did not need to act when processing their emotions.

Participant 3, an adult, demonstrated high *emotional autonomy* and *family enmeshment*. She described her experience as *enmeshed* because she provided unwanted, unhealthy family support to her mother via venting.

I went down for a family visit, and the dynamic was so terse, like I was on the computer while I was at home. Being like I need to find a therapist, right now, like today, I need to find a therapist.

As the one participant who did not demonstrate cohesion, Participant 3 showed high emotional autonomy because she sought emotional help from a therapist. However, the findings were inconclusive because Participant 3 described active help-seeking behaviors as an adult, not an adolescent. She did not provide specific examples that demonstrated family cohesion and high emotional autonomy.

Participant 2, also an adult, showcased low emotional autonomy. Her response suggested that she only received support and did not pursue help if other responsibilities needed priority, stating: "I feel like support came when people had the capacity, like when there wasn't something going on that like immediately needed to be attended to." As participants with high levels of family cohesion may have relied on support being provided, Participant 2 and 3 showed that a caretaker's emotional autonomy may have been influenced by their home environments.

Self-efficacy

Self-efficacy in the context of family caregiving described the extent to which an individual felt capable of adequately addressing a caregiving challenge/task. When participant responses showed or did not show feelings and/or actions in handling a caretaking situation, they were coded as self-efficacy. The responses included a high degree of self-efficacy (a belief they could handle a situation) or a low degree of self-efficacy (a belief they could not handle it).

All participants displayed high *self-efficacy*. Participant 5, an adolescent, explained that she had high *self-efficacy* because she demonstrated an action to handle a caretaking task: watching. "I helped [my grandma] watching so that she's not like destroying the kitchen, trying to escape down the street." Because Participant 5 explained prior experiences where she handled a caregiving situation, she believed she would successfully handle these situations in the future. This prospective outlook was prevalent in adolescent participants.

In contrast, adult participants believed they overcame a caregiving experience because it was necessary instead of believing they could approach caretaking themselves. Participant 2 (an adult in her early 30s) described caring for her brother as necessary to survive because she had a single mother: "So I think it was really just like this has to get done. We have to survive." Her response showed that her situation did not provide much choice besides providing care, suggesting that adult participants adapted to a situation in their adolescence due to a lack of other options. However, adults may have followed this trend because they were reflecting on experiences from their adolescence and not living through them at the time of the study.

Adolescent participants demonstrated *self-efficacy* differently from adults because none believed they would be long-term primary caretakers for their siblings (meaning their care would not extend to caregivers' adult years). This may have been related to the *cohesion* in their families because all participants explained that they had family members who would fairly distribute household tasks. Participant 1 stated that his parents did not want him to be the primary caretaker for their child, and their parents actively checked on their well-being:

My parents were always like you don't have to... watch him. [I]t wasn't very often, because they didn't want to put the burden on me. They [were] like... we still need to be responsible [because you're] still a child.

(Participant 1)

Similarly, Participants 5 and 4 helped care for their siblings because they had parents and other family members to share caregiving responsibilities. Participant 5 described how their

grandmother helps with their sibling: “My grandma will help him like, read. And I will like, go over numbers and letters... because I am always doing my own schoolwork. I don't take the time to sit down with him to help him with his” (Participant 5). In turn, Participant 4 shared about having many siblings to help with caregiving: “I have four siblings... And I guess that's where having a big family is a benefit. Because you could have a lot of people just helping him out. You know, you don't necessarily have to be there 100%” (Participant 4). Consequently, participants may have been more likely to display positive emotional impacts in adolescence if their family dyad was mainly *cohesive*.

Family Support

Another theme identified in participant responses was family support. The codes under this theme were *cohesion* and *enmeshment*. Both were terms used to measure support between family dyads; however, *cohesion* and *enmeshment* were used in this study as codes for healthy and unhealthy dyads.

Cohesion and Enmeshment

Family cohesion referred to suitable support between family members. Responses were coded as *cohesive* when participants described age-appropriate or healthy forms of support (determined by FACES IV Olson, 2008). *Family enmeshment* occurred when family members were fused in an emotionally or psychologically detrimental manner. Responses were coded as *enmeshed* when the participant described unhealthy forms of support, such as unwanted venting or age-inappropriate actions as defined by IADL and FACES IV. For example, Participant 3, an adult, stated:

I am this center peacemaker, like whether it's being there for my mom, because she has to vent because she's the one handling him on a day to day, or if it's... talking to my brother to try and de-escalate whatever conflict is happening between them.

Both *cohesion* and *enmeshment* determined the degree of family support that participants received in their families. *Family cohesion* suggested that participants received support from their families. Subsequently, there may have been a link in the amount of help participants needed to reach out voluntarily. Because participants with *family cohesion* did not need to find support to receive it, they may have been less likely to reach out.

If I am... in a bad mood, my parents will reach out to me and be like, ‘Hey, Are you okay? Do you need anything?’ And I also reach out to my brother... we usually reach out for each other whenever we notice that something is wrong. (Participant 1)

Participant 1 stated that his family communicated with each other and his parents underscored his adolescence as a primary reason for why Participant 1 was not his sibling's primary caregiver. This *cohesive* dyad encouraged a passive reception of help-seeking behaviors.

Family enmeshment implied that participants sought emotional support and initiative outside *enmeshed* situations. Participant 2 explained that she compromised her needs to care for her brother (an *enmeshed* situation due to lack of a healthy support):

We had to hurry because we had to be in an appointment so... whatever needed to be done got done... I couldn't go out sometimes because I would have to stay home and babysit for her because she had... stuff going on.

[But my mother] would try her best to make time for me and see what I needed and see what was going on with me.

However, when Participant 2 spoke to her mother to alleviate her emotional burden, she demonstrated *cohesive* behaviors, stating, “[her mother] would see what I needed.” The contrast in her two relationships may have indicated that emotional support and initiative were seen outside of the *enmeshment* she described. Regardless, the finding cannot be generalized to the entire population of adolescent caregivers, as only adult participants demonstrated *enmeshed* behaviors in their families.

Emotional Impact

Two codes did not fit under any theme category and stood alone as distinct concepts. *Emotional impact*, defined as the perception of care experience, was determined when the participant described feelings towards caregiving. This research defined positive and negative emotions with adjectives that have conventionally positive or negative connotations in colloquial speech.

Each participant had positive and negative *emotional impacts* when caring for their siblings. Responses were categorized based on any instance (rather than their holistic experience) that showed either a positive or negative impact. For example, Participant 2 described an example of a positive emotional impact when she explained: “I feel really grateful that I had the experience that I had because they shaped me... I wouldn't go back and change anything.” However, in contrast, Participant 5 described how she felt a sense of shame when they were not with their sibling, stating: “Because if like if I'm not near him, then I'm like, I feel ashamed.”

The four participants who demonstrated *family cohesion* tended to have more positive impacts when caring for their sibling and broadly described their caregiving with words like “love,” “being grateful,” and “feeling lucky” for having an autistic sibling. Meanwhile, Participant 5 explained that she felt “ashamed” if she was not near her brother.

However, *enmeshed* Participant 3 showed a prospective approach to caregiving, stating: “If I have kids, the rest of my life is about caring for somebody else. And if I don't have kids, I can just focus on myself until I absolutely have to be [Participant 3's brother]'s caretaker.” She may have reflected a different point of view coming from an *enmeshed* family environment in addition to her lived experiences as an adult. Thus, her *emotional impact* varied from Participant 5, an adolescent with a *cohesive* family environment.

Sibling Independence

Sibling independence was defined as the activities of daily life that siblings could conduct by themselves. The criteria for the code were whether siblings were independent or not independent. The code was found when the participant described sibling behaviors. Behaviors were classified as independent or dependent based on the IADL (Lawton & Brody, 1969) and the age of their siblings. Age was a classification factor because it would be inappropriate to assume certain types of independence for specific age groups (for example, an eight-year-old as financially literate). Thus, based on Lawton and Brody's (1969) scale, child siblings were only expected to be independent in categories A, C, D, and E in this study.

Participants 1 and 3 provided examples of their siblings accomplishing activities of daily living without assistance. Participant 1 explained: “He can do most of the things that he needs to do by himself... He even cooks for himself.” Similarly, Participant 3 described how their sibling made purchases out in the community and sought connections with other people: “He is kind of

now trying to buy his happiness and-and buy interactions... people sometimes... can sense his vulnerability or his um just strong, profound desire for connection.” Although Participant 3 described their sibling conducting independent activities, they noted the apparent vulnerability that came with living with ASD. Their sibling made independent efforts to connect with others socially.

In contrast, Participant 2 provided an example of a sibling with a low level of independence: “He had a very limited diet when he was younger... he needed to eat something very specific, and he needed to watch something very specific to like calm down and... decompress from the day.” Participant 2 described her brother’s specific diet growing up, and preparing his food was not independent per IADL’s section C.

Participants with independent siblings and *family cohesion* tended to have positive *emotional impacts* toward caregiving. Participant 1 stated that his brother could cook by himself, minimizing the time that he would need to dedicate to care. Similarly, Participant 3 stated a recent experience with her brother spending \$1,000 on OnlyFans, a subscription-based service to share pornographic content. In response, she expressed the need to speak with a financial advisor about his future finances. Although the response described her recent experience with her brother, she explained her adolescent years as ill-equipped and provided a similar example of when her brother attended therapy. Thus, dependent siblings may have been linked with an *enmeshed* family environment.

Discussion

Key Findings

These findings indicated that *cohesion* did not demonstrate a clear connection across individual experiences, but rather, a pattern involving *cohesion* and *enmeshment* became clear. These two codes tended to predict the directions of other codes, notably *self-efficacy*, *emotional autonomy*, and *sibling independence*. *Cohesion* tended to relate with codes classified as “positive” or “high,” as many participants often mentioned another family member in their support system (example of *cohesion*) when explaining the division of responsibilities in a caregiving situation (*emotional autonomy*). Two participants also explained that knowing someone with shared experience helped alleviate the burden of being a young carer. These findings suggested that while the theme of family support was essential in approaching the care burden, a possible broader theme of support may have been generalized for the caregiving population. One participant supported the concept in the interview, as she offered to be a “part of [CRV’s] community” due to their similar experiences, despite having no relationship before the research process. As such, these participants corroborated previous research that support systems reduce the burden and do not necessarily need to be familial support. This is similar to Sperling et al.’s (2020) findings because a robust support system reduces the caregiving burden.

When participants came from an *enmeshed* family, their responses indicated a high *self-efficacy* compared to participants from a *cohesive* family. For example, adult Participant 3’s continuously *enmeshed* behavior and dyad demonstrated high *self-efficacy*, as she was the only participant who indicated extensive future plans for her brother’s wellbeing. However, noting her negative *emotional impact* may have indicated that *enmeshed* dyads achieve a quality standard of life for the caregiving recipient at the cost of the caregiver’s psychological well-being. This statement aligns with prior caregiving literature and supports the hypothesis but is inconclusive because only one participant satisfied this criterion.

Connection to Family Systems Theory

These findings aligned with the theoretical framework of family systems, specifically circular causality. In general, circular causality refers to phenomena when people influence each other's behavior, and the source of the action cannot be pinpointed to one person. This recurring feedback loop was observed in the participants' responses to questions when they mentioned experiences of reinforced family caregiving expectations. Participant 2, who demonstrated both a *cohesive* and *enmeshed* dyad, was a salient example because her parent's role as an element within her family system unconsciously prompted both healthy and unhealthy behaviors. For example, emotionally healthy behavior was prompted when Participant 2's mother demonstrated appropriate expectations and did not require Participant 2 to perform a "function" to receive familial support. Conversely, Participant 2 also identified the support she received only after completing a caregiving task, or "function," within her family system. In both situations, Participant 2 would receive some kind of emotional validation from her mother, and the contextual factors leading up to the validation nuance the actions Participant 2 took to receive the same outcome. Because the other participants in this study did not demonstrate enough *cohesive* and *enmeshed* behaviors to identify this nuance properly.

However, the codes of *self-efficacy* and *emotional autonomy* challenged the family systems theory because participants implied their struggle to function emotionally when caregiving was a possible exacerbating factor. When observing Participant 2's response as an example of *self-efficacy* (referring to her brother's care as a necessity to "survive"), she could complete functions of daily living in exchange for socializing or personally fulfilling tasks. Thus, this research presented a fruitful area of further exploration, given prior literature's focus on physical and tangible methods of functioning instead of possible emotional impacts.

Emotional autonomy also challenged the concept of "intrapsychic" functions as a secondary factor for members within the system when exploring how boundaries were either respected or breached (noted as either *cohesive* or *enmeshed* behavior). For example, Participant 3 emphasized help-seeking behavior when she gained the monetary and emotional capacity to recognize her situation as unhealthy. However, Participant 2's reliance on available support emphasized her struggle to emotionally function, as "support came when people had the capacity." While these findings partially aligned with family systems, as participants were influenced by the "push and pull" dynamic of systems and did not impact their function to their siblings, their relationship between parents was significantly impacted. This harmful function between the element of parent and child was briefly explored in parentification literature, and exploring the significance of internal stressors within TDS/NDD sibling dyads could demystify the nuance that prior literature fails to address.

Adolescents' Unique Developmental Stage

Because adolescents do not have a fully developed pre-frontal cortex, they can be more sensitive to environmental influences, including relationships and social influences, than adults (Rakesh et al., 2021). Applied to caregiving, adolescents have many capabilities that younger children do not (e.g., driving, managing complex tasks) but still do not have the emotional maturity of adults, which may impede adolescents' ability to seek emotional support without the approval of a parent or guardian. This can exacerbate existing psychological struggles, especially given that an ineffective delegation of time to caregiving can encourage a withdrawal from daily life activities (Nakanishi, Nakashima, et al., 2022).

Thus, our findings indicated that adolescent caregivers may have benefitted from seeking support from their pre-existing family system (if they are unable to find or establish a social network), which encouraged either balancing or reinforcing feedback loops. However, adolescents' *emotional autonomy* and boundaries can be shaped by the support they receive in either an *enmeshed* or *cohesive* dyad. Participant 3 was a salient example, as her help-seeking behaviors in adulthood (not *enmeshed*) suggested that her access to resources as an adult broke feedback loops she could not breach as an adolescent (*enmeshed*). Though Participant 3 demonstrated a high *emotional autonomy*, her implied *emotional impact* demonstrated an example of a harmful function with other elements in the system. Hence, adolescents with unique vulnerabilities and sensitive developmental stages (Schribner, 2016), may need unique support to manage their role as a caregiver to avoid creating negative reinforcing feedback loops.

Implications

Our findings support existing literature, which indicated that the impact of caregiving on caregivers is complicated. While some caregivers may feel close to the person they are caring for, others struggle with the negative impacts of caregiving (Kates et al., 2023; Nakanishi, Richards, et al., 2022; Saragosa et al., 2022).

Our findings suggested that family support was strongly related to *enmeshment* and *emotional impact*, thus implying that young carers with low *emotional autonomy* and *enmeshed* families could experience negative *emotional impacts*. In other words, individuals with low *emotional autonomy* may be less likely to reach out for support compared with individuals with high *emotional autonomy*. Individuals with low *emotional autonomy* and an *enmeshed* family were prone to internalizing behaviors (Al-Yagon, 2015) and experiencing negative caregiving burdens (Daly & Lewis, 2000; De Stefano et al., 2022; Meier et al., 2014). Approaching the concern with support-based intervention in families may help mitigate *enmeshed* behaviors and include various measures (such as providing paid caretakers) to alleviate the caregiving burden.

At the systems level, some solutions may be found in policies that provide social support for adolescent caregivers. A possible solution based on the literature may be support-based intervention. Briefly, Gundersen (2012) looked at government outreach in Europe. While support was present in some government organizations, the complicated process often deterred caregivers from seeking support. Daly and Lewis (2000) agreed and explained that welfare states often privatize care or discern eligibility based on age requirements. Individuals who did not meet these criteria would thus be ineligible to receive the support needed. De Stefano et al. (2022) came closest to addressing intervention without discrimination against any background factors; still, their study was only conducted during the COVID-19 pandemic lockdown over a six-month period. Consequently, we were not aware of existing studies focused specifically on support-based intervention for the autistic-TDS sibling dyad, which may be a fruitful area of future research.

Our findings have implications for pediatricians who see children with special health care needs in their practices, as well as the medical schools that prepare pediatricians for clinical practice. If a child with special needs has at least one sibling, pediatricians have a role in assessing and supporting the family as a whole, including siblings who may be providing care. Pediatricians can support adolescents' health and, importantly, they can counsel parents on their expectations of their typically developing children in the context of a child with a special health care need (Rivera et al., 2023). Similarly, schoolteachers and staff who work directly with adolescents on a daily basis may be crucial sources of support and connection to services for adolescent caregivers (Gough & Gulliford, 2020).

Future Research

Future research may benefit from exploring *enmeshed* situations only and the possible psychological impacts. Furthermore, *self-efficacy* may have been affected by the participant's age. The adult participants, who both qualified as having *enmeshed* experiences, demonstrated high *self-efficacy*, whereas the adolescent participants did not. However, the adult participants had a non-nuclear family situation growing up and had significantly more life experience than the adolescents. For example, adult Participant 2 demonstrated both codes under family support in her family dyad: *enmeshed* (as a child) and *cohesive* (as an adult). The finding was unexpected, as nuance in *enmeshed* and *cohesive* environments was not a factor considered in the initial hypothesis.

Future research could also expand the participant group to include a more diverse group in terms of race and ethnicity, given that the majority of this community is Hispanic. Rather than interviews, focus groups may identify experiences common among adolescents across caregiving situations. Additionally, future studies could include adolescent caregivers and the parents of a child with a special health care need and an adolescent sibling (not necessarily from the same family) to gather various perspectives. Finally, future studies could explore the training and preparation available for medical students and other clinical providers to support families with children with special needs and how sibling caregivers are supported.

Strengths and Limitations

Because the original study design did not include adult participants, all questions were designed with current adolescents in mind, such as describing the current behavior of a sibling. However, this research adds to the caregiving literature by illuminating some of the unique experiences of adolescent caregivers "in real time" and including adults, which provided two participants with the time to reflect and added a layer of depth to our findings. Notably, adult participants expressed concerns about starting their own families and maintaining their own close relationships, which contributed to this study because adolescence participants were not articulating these concerns yet. Exploring these nuances with older adults also addresses the lack of complete cognitive development in adolescent brains. Compared with adults, adolescents may be more easily influenced by their surrounding social agents like parents (Riggs et al., 2014). Family systems theory supports this idea of a feedback loop, where any combination of a dyad's members can influence each other's behavior, but adolescents are particularly susceptible to internalizing certain behaviors or actions as they progress through the stages of psychosocial development. Future studies could compare adult and adolescent perspectives on the experience of adolescent family caregiving.

A lack of diverse cultural backgrounds may also have influenced the results, as CRV conducted interviews with a limited population. Notably, CRV's institution was a Title I high school in the Los Angeles area, with a predominantly Hispanic/person of color immigrant population. Thus, participants may have grown up with specific expectations about family roles and caregiving. Given that some participants also needed consent forms in Spanish, cultural expectations within the Hispanic community may have influenced participant experiences.

Moreover, the generational gap between participants and the interviewer may have influenced the results. Given that the adult participants (Millennials) were significantly older than the adolescent participants (Generation Z or "Gen Z"), their social environment may have differed. For example, the destigmatization of mental health in Gen Z spaces like social media might have encouraged the adolescents of this study to express their feelings more openly towards their families, creating a positive, reinforcing feedback loop. Meanwhile, the stigmatization of mental

health in prior generations may have impacted the views of Millennials. Millennial participants may not have felt comfortable openly expressing their views due to both the subject matter and the relatively young age of the interviewer.

Additionally, the interviewer's positionality as a recent adolescent caregiver and potential subconscious biases may have affected the interviews. Though CRV's lived experiences helped establish rapport between initially hesitant participants and mitigate the impacts of social desirability bias (Bergen & LaBonte, 2019), the interviewer's experiences may have influenced their non-generic probing approach. For example, when possible avenues to explore birth order emerged from the conversations, CRV's status as a younger TDS encouraged a reliance on existing theoretical frameworks to explore participants' thoughts objectively. Furthermore, initial plans incorporated possible distress to interviewees, but CRV may have subconsciously avoided probing further at specific key points to avoid their own distress. As such, some topics may have been insufficiently explored, but CRV made efforts to mitigate existing biases or assumptions by documenting their thought process and comparing their initial ideas against information presented in the existing literature. CRV's process was also continuously verified by a team of student mentors and the secondary author of this paper, who do not share the same caregiving experiences, to ensure responses were accurately represented. However, a future study could include a team of interviewers (one with lived experience and one without) to balance the potential aversion to difficult topics.

Conclusion

This study examined the emotional boundaries of adolescent caregivers when providing care for a sibling with clinically diagnosed autism. The results showed two driving themes in emotional boundaries: individual action and family support. Under these themes, the codes *cohesion* and *enmeshment* illustrated patterns across the remaining codes. Nevertheless, each individual provided a unique set of experiences—which can be examined through a variety of factors, like background experiences or the emergent codes identified—that may have benefitted from further analysis and explanation. Future studies may find it worthwhile to examine these codes further and instead identify terms in literature, use qualitative methods to understand human experiences and provide human-centered solutions like support-based intervention. Researchers may also choose to expand the sample size considered by this study or limit participants to a certain demographic that would share more experiences. This avenue for research would likely serve to mitigate many of the limitations produced by this study.

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