



# Stress and Coping in Autistic Young Adults

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## Abstract

**Introduction:** Half a million autistic youth will enter adulthood over the next decade. Support services to help youth successfully transition into adulthood are limited and not tailored to the autistic youth and young adult's needs. This study utilized qualitative methods to understand how autistic young adults experience and cope with stress during the transition to adulthood.

**Methods:** The study recruited 15 autistic young adults aged 18–25 years. Each participant completed a short demographic survey and individual interview. Interviews were conducted online via Google Docs or in-person based on the participants' preference. Three researchers organized and coded the data using a thematic approach.

**Results:** Based on our analysis, three themes emerged. Within the first theme, young adults in this study described experiencing a great deal of stress and provided examples of how it manifested in physical and emotional ways. In the second theme, youth described that the causes of this stress stemmed from general problems handling new or multiple responsibilities and specific problems in school, work, financial responsibilities, and social relationships. Finally, young adults described using various coping mechanisms including relaxation techniques, use of technology, and friends and family social support.

**Conclusions:** The study findings can help service providers and family members find new ways to help autistic young adults manage their stress. This study provides a unique understanding of stress and coping from the autistic individuals' point of view. Stress is most often derived from managing new responsibilities in general and school, work, money, and relationships in particular. Tailored support services that follow the individual from adolescence through adulthood are needed to manage these stressors. Researchers and service providers can utilize these recommendations for future program development. Furthermore, the method used in this study can be replicated to facilitate autistic individual input on future program development.

**Keywords:** stress, coping, independence, autistic young adults

## Community Brief

*Why is this an important issue?*

Few studies have examined what autistic young adults go through as they move from childhood to adulthood. Moving from high school to more adult duties is stressful for all young adults. It is unclear how autistic young adults deal with these changes.

*What was the purpose of this study?*

We wanted to better understand the experiences, stressors, supports, and coping styles of autistic young adults as they move from childhood to adulthood.

*What did the researchers do?*

We asked autistic young adults to describe their experiences, stressors, and how they cope as they age from teen years to adulthood. Fifteen autistic young adults were interviewed through Google Document or in-person interviews. To analyze the data, three researchers read each interview to find ideas and experiences those young adults shared. The researchers met many times to discuss the shared ideas and experiences they found. Researchers discussed these ideas until they agreed on what the main shared ideas (or themes) were. Two researchers then reread all the interviews to match ideas with the interview quote.

*What were the results of the study?*

Researchers found three ideas (or themes) that all or most autistic young adults talked about. (1) Young adults said that they felt stress in physical and emotional ways. (2) Dealing with new responsibilities, many responsibilities, and relationship problems were their main causes of stress. (3) Autistic young adults said that they had different ways of dealing with their stress. Some young adults used meditation and others played games on their computers or phones or looked at pictures to deal with stress. Many young adults also said that they get help from family and friends when they are stressed out.

*What do these findings add to what was already known?*

These findings help us better understand what stressors autistic young adults had and how they deal with this stress. Most studies ask caregivers questions about their young adults. Learning about stressors and ways to deal with stress using the young adult's own words is an addition to what we previously knew or what was published. Furthermore, the use of Google Doc discussions to collect data is new and was a good method of data collection.

*What are potential weaknesses in the study?*

We only had 15 autistic young adults agree to be in the study, and most were white and male. Young adults with severe communication limits were not able to be in the study.

*How will these findings help autistic adults now or in the future?*

We know more about the ways autistic young adults feel stress and anxiety and how they deal with it. This information can help service workers give autistic young adults the support they need. The findings from this study can inform new interventions and can help health care workers, support service workers, and family members help autistic young adults deal with their stress and provide more ways to deal with their life stress.

## Introduction

**I**N THE PAST 20 YEARS, we have made huge progress in diagnosing autism spectrum disorder and providing services for young children. However, we have not provided the same level of care for autistic adolescents and young adults.<sup>1</sup> For example, the Interagency Autism Coordinating Committee has designated young adult and adult research and service as a priority area since 2010; however, only 2% of federal and private research funding was allocated to these age groups in 2016.<sup>1</sup> An estimated 50,000 autistic children age into adulthood each year, many going without needed services and support to successfully meet their goals or maintain a good quality of life.<sup>2-6</sup> More research focusing on this age group is needed to better understand and meet their needs.<sup>1,5,7</sup>

The transition from childhood to adolescence and adulthood is tumultuous for all individuals and requires increased and divergent supports. The shift from school to home, work, or higher education is particularly challenging for autistic young adults.<sup>8,9</sup> Formal education, support, and medical services decrease after exiting high school, making this transition isolating and challenging for autistic young adults and their families.<sup>6,7,10,11</sup>

Success in higher education is hard for autistic individuals due to social anxiety, additional mental health needs, and lack of social and other supports.<sup>2,4,12</sup> Similarly, studies examining the quality of life for autistic young adults and adults indicate lower quality of life due to sleep issues, lack of daytime activities, lack of independence, and mental health conditions.<sup>3,13-15</sup> These issues are pervasive for autistic young adults and affect their daily lives and overall well-being.

Autistic young adults tend to have a higher incidence of mental health conditions co-occurring, but there are limited data regarding how these conditions manifest themselves in adolescents and young adults. Anxiety disorder and depression are relatively common in autistic adolescents and young adults and surpass those without autism.<sup>16-18</sup> In a comparison study, autistic adolescents reported more stressors and fewer coping mechanisms than their typically developing peers.<sup>9</sup> Anxiety and depressive disorders in autistic adolescents have often persisted into adulthood with severity increasing until middle age.<sup>18,19</sup>

Using survey data, quantitative research has identified an increase in mental health disorders, but a direct conversation with autistic individuals can provide additional insight.<sup>18</sup> Qualitative research increases understanding of an issue from

the participant's point of view.<sup>20</sup> Individual interviews with autistic young adults have been an effective tool to gaining insight into various aspects of the person's lived experience of transitioning into adulthood.<sup>21-23</sup> The current study utilized a unique qualitative methodology to promote inclusivity and better understand the stress and anxiety autistic young adults are experiencing and what coping mechanisms they use. This method provided autistic young adults with an open forum to conceptualize and define stress and coping on their terms and in their preferred method of communication.

## Methods

Young adults were eligible to participate in the study if they were aged from 18 to 25 years, had an autism diagnosis [self-report ( $n=8$ ) and/or clinical record review ( $n=7$ )], were able to read and speak English, and were able to engage in the interview as measured by young adult self-report.<sup>24</sup> The study team utilized autism treatment and support agencies across the U.S. Midwest to distribute study information. Study fliers and recruitment material were distributed by mail/email, in local clinic settings, and social media sights.

Interested participants contacted the research team to complete a screening questionnaire to determine eligibility. During this initial encounter, staff described the study and activities included in participation and encouraged questions. The staff made it clear that the participants had the option to opt out of the study at any time. Research team members obtained institutional review board approval from their university before recruitment activities commenced.

### Data collection procedures

Subject participation consisted of semi-structured interviews lasting between 30 and 60 minutes. Autistic young adults were emailed interview questions approximately a week before the scheduled interview.<sup>24-26</sup> Two potential modality options were available to autistic young adults participating in the study: a synchronized online interview utilizing Google documents ( $n=10$ ) or in-person interview ( $n=5$ ) to improve young adults' comfort and participation. Each modality started with a description of the study and consent waiver, completion of a short demographic and health status survey.<sup>27</sup>

Online Google documents allowed the interviewer and participant to type into a synchronized Google Doc as their method of communication. The interviewer asked original questions and follow-up questions related to the participant's responses in real time within the same online document. The interview was conducted in a private clinic room for in-person interviews to answer the interview questions verbally.

Researchers working to understand the lived experiences of autistic individuals and others with communication difficulties have a long history of using creative data collection methods.<sup>28-31</sup> Previous studies utilizing autistic individuals have shown that online data collection through discussion forums, web-based open-ended questions, email exchanges, and journal entries have facilitated information data collection and improved communication for people with communication challenges.<sup>30,31</sup>

Previous research utilizing typically developing participants indicated comparable qualitative data collections (number of unique codes) and results from both in-person and

online methods.<sup>32</sup> We utilized Google Docs as a unique method of data collection to facilitate participation for autistic young adults with different levels of communication or social communication challenges and to reduce travel burdens for participants living in rural areas.

Within this study, online and in-person interviews had similar interview durations, but in-person transcripts were longer at an average of 11 pages and online transcripts had an average of 7 pages. While online participants' transcript lengths were shorter, topics covered within discussion were similar to those participating in in-person interviews. Participants participating in online and in-person groups did not differ in terms of themes or subthemes.

### Measure

The interview guide included 14 open-ended questions focusing on the autistic young adult's current life experiences. The guide compiled recommendations from autistic young adults and caregivers, as well as previous research.<sup>9,21,33</sup> An autistic adult, several caregivers, and clinicians reviewed the interview guide and provided feedback before its use. The interview guide covered topics of independence, education attainment, employment and education aspirations, personal goals, and stress and coping.

### Analysis

Qualitative data were analyzed through an iterative process involving several stages of discussion, coding, categorizing, theme development, and review to ensure the credibility and rigor of the analysis.<sup>34-36</sup> We utilized an inductive approach to data analysis working diligently to stay close to the data at each analysis point. The thematic analysis utilized a reflexive approach to code and organize data, including initial and axial coding, analytical memos, and organizational matrices and reports.<sup>37,38</sup> Finally, we used a semantic level of data coding to again stay close to the data and true to our objective of giving autistic young adults a forum to define stress and coping on their terms.

The first author completed or assisted with each interview, and both authors worked jointly on the data analysis. Using ATLAS.ti, a qualitative data analysis program, the data were coded and analyzed.<sup>39</sup> While analysts coded data in ATLAS.ti, they also utilized paper transcripts and frequently consulted the literature to ensure a deep understanding of the data and analytical rigor.<sup>40</sup>

The authors first worked to identify themes observed in the data and develop a codebook of prominent themes. Each author read three interviews independently and developed an initial list of themes/codes based on the data. The authors met and discussed initial impressions of thematic categories and created a preliminary structure of primary codes. A third team member independently reviewed the transcripts and compared their impressions with the initial list of code categories. The team met several times to review individual codes and developed a shared list of prominent codes to guide data analysis.

The authors again utilized an iterative consensus-building process to code the data.<sup>37,38</sup> To increase the dependability and credibility of the data and findings, both reviewers coded three transcripts to establish interrater reliability. Reviewers met to discuss codes from each transcript, review discrepancies, and

modify the coding structure. The examination of the code agreement resulted in ~70% agreement. The analysts reviewed the code definitions, clarified any differences, and coded several more transcripts.

The team compared codes and determined that the coder agreement was closely aligned (95% agreement). The team conducted a review of discrepancies and established reliability, and the second author then independently coded the remaining transcripts. Upon coding completion and data visualization of code frequency, the authors identified connections between codes and synthesized data into themes. The final set of themes and subthemes met recommended criteria for both internal homogeneity and external heterogeneity.<sup>41,42</sup>

## Results

Study participants included 15 autistic young adults aged between 18 and 25 years (mean = 21.3 years). Most autistic young adults were male (80%), White non-Hispanic (87%), and were currently attending school (67%). Most participants stated that they had good self-care skills or rated themselves as mostly independent (87%; Table 1). The following sections and Table 2 describe these themes in detail with pseudonyms used to protect the participant's identity.

### *Theme 1: Physical and emotional responses to stress*

All participants described how they experienced stress, with many describing in great detail how it manifested within their bodies, thought processes, and ability to function. Participants described experiencing stress both physically and mentally.

TABLE 1. PARTICIPANT DEMOGRAPHIC CHARACTERISTICS (N=15)

Variable	% (n)
Gender (male)	80 (12)
Race/ethnicity (White, non-Hispanic)	87 (13)
Currently attending school (yes)	60 (9)
Highest level of education	
No high school degree	27 (4)
High school diploma	67 (10)
Associates degree	7 (1)
Currently in school	
No	40 (6)
Yes, in high school	13 (2)
Yes, in college	47 (7)
Currently employed (part-time or full time)	
None	47 (7)
Part-time	47 (7)
Full time	7 (1)
Self-assessed level of independence	
Mostly or completely independent	40 (6)
Good self-care but still need some help	47 (7)
Some self-care skills but need a lot of help	13 (2)
Current living situation	
With biological or adoptive parents	67 (10)
Supportive living facility	13 (2)
With roommates	7 (1)
Alone	13 (2)

**Physical manifestations.** In half of all participants, physical symptoms related to stress included pain, discomfort, gastrointestinal (GI) symptoms, and sleep disturbances. Joshua described stress as overall negative feelings in his body saying he was in "pain and misery." Similarly, Chris said he "felt terrible" and Brianna described "feeling tense" when she was stressed.

Other participants described specific ailments. Gabriel said when he experienced stress, "I start shaking and shivering. Sometimes I get a headache." Chris and Nick also described, "getting headaches." Several participants described breathing problems as Emily said, "[I] just feeling it [anxiety] in the chest." Emily stated that sometimes stress affects her digestive system, saying stressful things made her "have to poop a lot." She went on to describe similar issues saying, "Yeah. Digestive system, and sometimes in the morning I feel nauseous, and I wake up just because it's, it's the school and I'm just tired of it." Jo described sleep issues stating, "Sometimes I have trouble going to sleep .... when I'm [worried about] a new situation."

**Mental manifestations.** Autistic young adults described mental and emotional strain when feeling stressed. Both Jacob and Chris described being "overwhelmed" when they experienced stress. Gabriel stated, "I get nervous that I won't be able to handle something. I start worrying and worrying ... I'm not really sure how to describe it." Others described stress as making them feel angry and frustrated. Andrew stated that stress made him, "Anger irritation sadness," while Jessica said that she felt, "Frustrated and aggravated." Chris described behavioral issues saying stress leads him to have "meltdowns .... get mad and I get stuck."

Others described these feelings in more abstract ways. Jessica described stress feeling like, "a multiple-choice question in your head, like A, B, C, or D. Which one should I pick? With the computer typing in your head and like a toy box filled with toys. Crammed to the max." Will combined many of these emotions and descriptions saying, "When I feel stressed it kind of puts me in this self-defeating cycle almost. I feel the world almost closing in on me and I get too anxious to try and push back on it if that makes sense. I can get really frustrated." Brianna also described a lack of control stating, "I feel trapped like I'm stuck in a bad situation and that I may not be able to do anything about it, since most of the time my stress comes from feeling like I'm not in control of my circumstances."

### *Theme 2: Responsibility and relationship-related stressors*

Participants' stressors fit into four subthemes: Managing Responsibility, School and Work Challenges, Financial Issues, and Social Interactions and Relationships.

**Managing lots of responsibilities.** Navigating an adult life with multiple responsibilities was a source of stress for most participants. As Gabriel described, participants worried about responsibilities that come with age saying, "I'm not always sure I can keep up with all the little tasks that come with full independence ... I guess I'm not used to a large number of small responsibilities." Brianna described

TABLE 2. AUTISTIC PARTICIPANT'S PERSPECTIVES ON STRESS AND COPING

<i>Subthemes</i>	<i>Quotes</i>
Theme 1: Physical and emotional responses to stress Theme 1A: Physical manifestations	<i>Sometimes stress makes me feel slightly nauseous ... also generally stress drains my energy over time if I am stuck in a stressful situation for a long time</i>
Theme 1B: Mental manifestations	<i>Overwhelmed ... Frustrated [Stress] sometimes makes me feel like I dislike myself, or maybe disliking/criticizing myself is where the stress comes from</i>
Theme 2: Responsibility and relationship-related stressors Theme 2A: Managing lots of responsibilities	<i>Sometimes [worried] because you can and will be held accountable for bigger things</i>
Theme 2B: School and work challenges	<i>Stress sucks. I usually get it when there's a lot of school work piling up or when we're getting really busy at work</i>
Theme 2C: Finance	<i>There are still some responsibilities that I have not experienced yet, like paying bills</i>
Theme 2D: Social interactions and relationships	<i>When people don't understand autism Just like people's accountability and stuff</i>
Theme 3: Participants manage stress in various ways Theme 3A: Relaxation	<i>Usually breathing, rubbing my temples, and sort of going to my happy place helps get me out of it. Go for a walk or say "I need a break"</i>
Theme 3B: Use of technology	<i>Sometimes I'll look at pictures on my phone of my pets or other things that bring me calm or happiness. I play videogames. That helps sometimes</i>
Theme 3C: Family and friends	<i>Try to get advice from people who have done this a lot in their lives. Sometimes I tell my friends about things that are stressing me out</i>

something that likely resonates with most adults when saying, "Feeling tense, having too much work and too little time to do it."

The consequence of not being able to meet these responsibilities was a further stressor. Austin said that he was worried about, "Things going the wrong way." Emily was worried that she may not be able to transfer to this next stage in life, stating, "That it might not happen, I'll just stay at home for the rest of my life, maybe become homeless." Chris, like many participants, listed the potential mistakes they were worried about, "yes I worry I will mess up ... Like with the tea. I burned the water. I forget my meds. I need to know more about money."

**School and work challenges.** Within this study, most participants were in high school or attending a college (80%), 53% were working either part-time or full time, and all participants had examples of school or work stress. Tyler and Jacob gave specific examples of school stress saying "tests" and "when giving a presentation" were both stressful situations. Similarly, Emily and Chris said that they got stressed about "getting assignments done" and "too much homework."

A few participants described their feelings of stress when they had to pull back from responsibilities. Gabriel stated, "When I first started going to [college name], I jumped right in with two big classes ... and couldn't keep up with the course load. It got to the point where I had to drop them because I just couldn't mentally handle the course load." Daniel felt a lot of pressure to maintain employment saying, "Telling my fiancé and her family that it didn't work out with [store], everyone was counting on me."

**Finance.** Similar to school and work, participants were worried about financial challenges. Will discussed what stress meant to him saying, "I guess the first thing I see when I think of the word stress is people in stressful situations. I kind of have this picture in my mind of someone staring at a bill that says past due on it."

Others described "having financial responsibilities" and "financial problems" as sources of stress. Tyler also described financial worries stating, "Just kind of try to do what I am supposed to do. Pay Bills ... And just everyday people and stuff ... Like money and gas." Nick combined his struggle with general and financial responsibilities saying, "There are still some responsibilities that I have not experienced yet, like paying bills, filing taxes, and insurance-type tasks." Chris also said he needed to "know more about money" and how to "make sure to pay bills." The combination of having to do unfamiliar activities and built-up stress around money seemed to coalesce in many participants' discussions of financial stress.

**Social interactions and relationships.** Participants described stressful interactions and relationships in a myriad of ways. Joshua described a potentially dangerous living situation when talking about his housemate, "He throws a huge tantrum and punches holes in walls." While Joshua avoided these situations by, "Go[ing] to my room, close the door." He described it as one of his biggest stressors. Tyler described the stress of having unreliable coworkers saying, "Just like people's accountability and stuff ... [they'll be] like saying, 'I'll be back after lunch,' and then an hour and a half later and they finally come back from lunch."

Other participants described how social interactions can be stressful and confusing. Jessica stated,

When people don't understand autism and ... make fun of people who use sensory toys ... When people tease me, because it's like, A, are they teasing you? Are they trying to antagonize you, let your autism get to you? B or C, are they trying to scare you? Or D, all of the above? Kind of like that.

Brianna was more self-effacing saying, "Another source of stress for me is whenever I make any mistake ... especially any kind of social faux pas."

Additionally, two participants said lack of relationships caused stress. Jo said, "Finding a girlfriend" was stressful. Austin said that he felt stressed, "in the past (when) I couldn't go home or see my family a lot." While social interactions were stressful across the board, participants showed complex emotions such as Joshua's feelings of fear and frustration and Jessica's feelings of confusion and worry, related to various types of social engagement.

### *Theme 3: Participants manage stress in various ways*

Although methods vary, participants consistently describe strategies that helped them "clear my head," "calm down," and "help me a lot with stress and anger." Coping subthemes included relaxation, use of technology, and seeking support from family and friends.

**Relaxation.** Several participants described frequent use of relaxation methods such as rubbing the temples and meditating. Two participants described daily or near-daily meditation practices to reduce stress and anxiety. As Will stated, "Another way I deal with my stress is that I try to meditate once a day for at least 5 to 10 minutes." Emily also described her main way to deal with stress as, "Ginger tea and mindfulness." She gave a detailed description of her meditation practice stating,

I remember what my brother pretty much said about mindfulness was pretty much to just not think about it, like leaving ... Just try thinking about nothing .... I would just try reading signs and stuff without any other thoughts popping up, like without having a judgment about it or without it stirring an emotion.

Other forms of relaxation included "taking a bubble bath," "using a weighted blanket," and manipulating "sensory toys." As Jessica stated, "When I'm out in public ... sometimes the crowds or sometimes the noises bother me. So, instead of acting out or acting frustrated, I use those kinds of sensory toys ... to calm me down."

Experiencing nature and being alone were other common ways to relax and handle stress. As Gabriel said, "I do enjoy taking long walks ... It helps clear my head a bit." Similarly, Daniel described, "Stand outside for a while in sun with my dogs ... It helps calm down." Joshua described needing space stating, "I just tell the staff I'm going out to the car and wait in the car by myself [to get alone time]."

**Use of technology.** More than half of the participants described using technology as a source of distraction, a way to relax, or add joy to their day. Gabriel echoed several participants' perspectives when saying, "When I get stressed, a great

thing that helps me is to distract myself from it for a bit by watching YouTube videos or playing a video game." Daniel and Jacob described ways they used technology to get away from everything. While Daniel "watch a show or play[ed] Xbox," Jacob said that he "Listen[ed] to music and/or [would] sing." Emily described a unique relaxation method at work stating, "I just do data entry now. I just look at numbers on a screen and then put them on there. I find that kind of soothing."

Nearly half of participants played video games as a source of relaxation, distraction, and/or enjoyment. Andrew described multiple uses of video games when he said, "[I] go lay down in my room or play some video games, things like Kirby where it's so cheerful and fun you can't stay mad or a racing game where you can turn your frustration into concentration." Only two participants used technology or other methods to work through their stress. Brianna described, "Keeping timers on my phone to go off in advance for stuff has probably been one of the best things I've done to keep my head above the water of time management." Similarly, Gabriel stated, "When I get stressed ... [I] make a strategy for dealing with the source of my stress, such as doing a paragraph of an upcoming essay a day."

**Family and friends.** Leaning on family and friends was a widely mentioned coping strategy to help strategize, get advice/direction, and/or vent. As Brianna stated, "My mom sometimes talks to me about strategies to deal with stress and sometimes I tell my friends about things that are stressing me out." Chris, Will, and Emily learned their meditation and relaxation strategies from their parents and support group. Chris described, "They [sister and mom] talk to me. Help me breathe." Will learned about "taking deep breaths when I'm upset is something I've been told by teachers, my parents, therapists."

Several participants talked about getting advice to help deal with problems. Gabriel described taking a difficult college course and said that he succeeded by, "[making] sure to get recommendations from instructors." Several participants turned to peers for advice. Nick said, "Try to get advice from people who have done this a lot in their lives. I feel like this would be a great start in reducing the amount of stress in learning these responsibilities." While Emily did not seek advice directly from friends and peers, she described another form of support stating, "I've noticed that what helps the most is to be able to be with peers and friends and just to observe them and how they cope with stress and talk to them about it." She also acknowledges that having more friends would be helpful in this regard stating, "So I pretty much just need more friends that are my age."

Other participants described managing stress by talking about their problems. Will stated, "I also like talking to my friends or my girlfriend. Sometimes just venting and letting it out helps a ton." Both Chris and Austin described this briefly as Chris stated, "talk[ing] to mom," and Austin said, "Talk to people I trust ... My family, Psychologist." While participants had many stressors, they also had numerous coping mechanisms and supporters to help them move past the stress of young adulthood and adult life.

## **Discussion**

This study worked to better understand what stressors autistic young adults experience and how they manage this stress. Participants described how stress manifested

in their bodies and thoughts, causes of stress in their lives, and coping mechanisms they used to move through stress.

Participants described physical and psychological effects of stress using specific and often literal language. Specifically, participants described sleep and GI problems that they felt were related to stress. There is a large body of research documenting poor sleep quality in autistic individuals.<sup>13,43</sup> Sleep quality has also been shown to affect the perceived quality of life for autistic and typically developing adults, which may explain increased feelings of stress without our sample.<sup>14</sup>

GI problems are also common in autistic individuals and often increase when anyone is dealing with stress.<sup>44,45</sup> While this is not new and certainly not specific to autistic individuals, the combination of sleep and GI problems with moderate to high levels of stress during the transition to adulthood is concerning. Caregivers, medical providers, and support service providers should be aware of each of these issues individually and in combination and work with the autistic individual to identify appropriate coping strategies.<sup>9,46</sup>

In this study, autistic young adults were able to identify many different stressors and describe how these stressors had negative implications on their lives. Studies that have explored this issue similarly identified increased responsibilities, education, and employment challenges, and financial management are common stressors.<sup>9,21,22,33</sup> Similar to our findings, First et al.<sup>21</sup> reported that autistic adolescents felt stressed and overwhelmed by their current responsibilities and were worried about additional responsibilities. They also identified a lack of knowledge about available resources from both caregivers and autistic adolescents, identifying an important need for social workers and other health care providers to connect families with essential and support services.<sup>21,47,48</sup>

Comparisons with typically developing peers indicate that both groups have similar levels of stress related to academic success, but autistic young adults had more nonacademic stressors and described fewer opportunities to express or release stress.<sup>9</sup> Taken together, this signifies the importance of talking about stress with autistic young adults in various settings (i.e., school, health care, support services, and home) and further developing creative ways to release stress.

Most participants, regardless of current employment or education status, experienced stress about successfully managing work and/or school. Challenges with executive functioning such as initiating new activities and switching activities may affect a young adult's actual and perceived ability to successfully find/maintain employment or higher education.<sup>49</sup> The connection between executive function difficulties and increased levels of anxiety and depression has been shown in autistic adults.<sup>49</sup> Understanding the connection between stress, mental health, and quality of life helps inform the development of appropriate interventions and the importance of funding for these services.

Many interventions have been shown effective in supporting various young adults in the transition to adult life.<sup>50,51</sup> Cognitive behavior therapy shows promise in its ability to reduce anxiety and targets various psychological barriers to new or challenging activities for autistic young adults.<sup>50</sup> Similarly, educational programs related to executive functioning skill building and financial management have been developed specifically for autistic young adults and people with disabilities.<sup>51-54</sup>

Autistic young adults had a plethora of strategies mostly focusing on relaxation techniques, use of technology, and getting support from family and friends. Family and social support is widely discussed in the literature and mirrors our findings with caregivers providing the majority of support and guidance.<sup>21,33</sup> The number of participants giving detailed descriptions of relaxation practices was surprising. Many participants described the use of meditation, self-soothing, and breathing exercises. Research in this area is lacking, but initial examination has shown the possible benefit of meditation for autistic children.<sup>55-57</sup>

Autistic young adults used technology as a source of distraction, pleasure, and to a lesser extent problem-solving. Digital interventions for autistic adolescents have primarily been computer-based and focus on social skill development, resulting in positive but small overall improvements.<sup>58,59</sup> One study found that autistic high school students used technology in and out of school to support learning, stay organized, and increase communication. Autistic adolescents reported that technology relieved anxiety and stress as well as improved independence and socialization.<sup>60</sup> Several survey-based studies have indicated that autistic individuals have higher rates of problematic internet and video game use than their typically developing peers.<sup>61,62</sup>

While it is not clear how much time autistic young adults spend on technology and gaming systems compared with their typically developing peers, gaming disorders are significantly higher in autistic individuals.<sup>62</sup> Participants in this study did not describe such behavior but rather described playing video games as a form of relaxation and release. Future research combining survey and interview data would provide a fuller and more nuanced picture of autistic young adults' gaming and technology use and how it can be used to promote coping skills. Terlouw et al.<sup>63</sup> similarly argued that autistic opinions must be included in digital intervention design as their perspective and goals often differ from caregivers and professionals.

This study presents in-depth descriptions of stress and anxiety autistic young adults are handling and solutions that youth are utilizing to deal with this stress/anxiety. Reading these firsthand accounts provides additional context to survey-based descriptions of autistic young adults' stress or autistic and typically developing comparison studies. Based on their own reports, autistic young adults need purposeful and various ways to relieve their stress. Previous research supports this idea and the importance of having multiple support systems to assist young adults in dealing with stress rather than leaving this to the individual and caregiver.<sup>2,9</sup>

### Limitations

This study utilized qualitative data to explore the experiences of specific autistic young adults in detail; thus, data may not be generalizable to all autistic young adults. While we had autistic individuals, caregivers, and clinicians review and provide feedback on the interview questions, these groups did not contribute to the study's design or analysis of the data. Furthermore, while the first author has a neurodevelopmental disability, no one on the research team is autistic. The study sample has limited diversity concerning participants' communication level, race, and ethnicity.

The study required participants to be able to read/write or verbally communicate and the majority of the sample rated themselves as mostly independent or needing only some assistance. Autistic young adults with differing communication and cognitive and/or physical abilities were excluded or chose not to participate in this study. Because our study population resided in urban or suburban areas in the Midwest (Table 1), the data do not reflect the experiences of autistic young adults from larger urban or small rural areas or racial and ethnic minorities.

Additionally, it is important to point out that this study lacks gender diversity, with 80% of participants identifying as male. This is a consistent problem in autism research and service provision. Due to our lack of gender diversity, our findings may have limited application to autistic individuals who identify as female. Additional work needs to be done to ensure female-identifying autistic individuals and their views are fully represented.

This study used online synchronized Google Docs to collect the majority of the data. Participants were allowed to conduct interviews online utilizing synchronized Google Docs or participate in in-person interviews. This data collection method supports equal participation for autistic individuals with different levels of communication and allows for data collection with participants when distancing is important, or transportation is an issue. To the best of our knowledge, this is a new technique that has not been utilized in previous research and thus requires additional exploration.

There were benefits and challenges to using synchronized Google Docs to collect data. A benefit of using synchronized Google Docs was allowing participants more choices and also allowing those living out of the area to participate. It was convenient and reduced time and cost for transcription. Some participants had challenges utilizing Google Docs. Access to phone-based communication helped to troubleshoot any potential problems. Interviewers need to ensure that the young adult or autistic participant is answering questions for themselves. On one occasion, the interviewer had to ask a caregiver to allow the participant to answer for themselves. A final challenge, as described earlier, was that the transcripts from Google Doc interviews were shorter in length than in-person interviews. Future researchers utilizing this method will want to think creatively about facilitating text communication.

### Implications

This study used unique qualitative methods to gather insight into how autistic youth experienced and coped with the stress of transitioning into adulthood. Autistic young adults are experiencing stress, managing new responsibilities in general and school, work, financial responsibilities, and relationships in particular. Autistic young adults in this study also articulated various coping mechanisms (relaxation, technology, and friends/family) to provide support through the transition to adulthood. Addressing these stressors and incorporating preferred coping techniques into current interventions and support services will improve the quality of care for autistic young adults.

Our findings identify the need for more support services of autistic young adults that follows the individual from adolescence through adulthood, with tailored services based on the individual's needs. Furthermore, the standard should be

consulting with and getting feedback from autistic young adults when developing programs and interventions. While identifying these themes improves our understanding of autistic young adults' experiences as they transition into adulthood, further research is needed on how these themes and experiences are similar to and different from those experienced by typically developing young adults.

### Authorship Confirmation Statement

N.C.-Z. conceptualized the study, conducted qualitative data collection, assisted with data analysis, and revised the article. O.O. assisted in qualitative data analysis and wrote the first draft of the article. Both co-authors have reviewed and approved the article before submission. This article is being submitted only to *Autism in Adulthood*. It will not be submitted elsewhere while under consideration. Should it be published in *Autism in Adulthood*, it will not be published elsewhere—either in similar form or verbatim—without the permission of the editors.

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### Ethical Approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee (Agency for Healthcare Research and Quality) and with the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards.

### Disclaimer

The authors take sole responsibility for the content of this report, which does not necessarily represent the official views of the Agency for Healthcare Research and Quality.

### Author Disclosure Statement

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