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# **Editor's Message**

It is a pleasure to share with you the 23rd issue of Journal of the International Association of Special Education (II-ASE). Thank you to all of you who submitted manuscripts, conducted reviews, and assisted with managing the journal issue. JIASE is a critical part of IASE, disseminating research findings, outlining conceptual frameworks, and sharing examples of practical implementation ideas related to special and inclusive education as well as the transition of youth with disabilities to adulthood.

Reflecting an ongoing issue in the U.S., the issue opens with a conceptual article titled, "Disproportionate representation of culturally and linguistically diverse students with special needs: An ongoing concern." This article provides a historical overview of the overrepresentation of culturally and linguistically diverse students in special education programs in the United States.

The second article, titled "Virtual intervention to build reading fluency for struggling readers in India: A preliminary study," studies an implementation of a formative assessment developed in the U.S. and then adapted to the Indian context, with a component of a virtual reading intervention.

In an article titled "Autoethnography and interpretative phenomenological analysis (IPA) understanding the challenges and strategies for parents of children with autism in Saudi Arabia," the author, who is a Saudi mother of a child with ASD, combines her own lived experience narrative with online interviews with two co-participants (Saudi mothers) raising a child with ASD in Saudi Arabia.

In "An international investigation of psychological distress among special education majors during the COVID-19 pandemic: Egypt, Turkey, and the United States," the authors investigate the uncertainty experienced by university students in Egypt, the United States, and Turkey during the recent pandemic.

The praxis article in this issue introduces the topic of "Timer visual formats and literacy-based behavioral interventions," aiming to expand the literacy-based behavioral intervention literature by exploring the impact of self-regulation countdown timers on young children during a home-based self-care routine.

It is a privilege to work with such talented and committed authors from all over the world to feature topics that affect children and youth with disabilities, their parents, teachers, and caregivers.

If you would like to share your research or practices, JIASE is a wonderful international outlet for others to learn about and implement your work.

At JIASE, we are committed to working with first-time authors and contributors who may have not published in a peer-reviewed journal before. We also welcome contributions from seasoned and returning authors. The JIASE management and review teams are well prepared to work with you to develop a publication you will be proud of.

We are always seeking members who would like to serve as consulting editors for JIASE. If interested, please contact me directly for more information. Also, please consider submitting your work for publication in future JIASE issues. Publication submission guidelines are located on the IASE website at https://iase.org/journal as well as at the end of this journal issue.

Thank you for being a member of IASE. We hope to see you at the 18th Biennial IASE Conference in Pilsen, Czech Republic, from June 28 to July 1, 2024!

With warm regards, Renáta Tichá, PhD Editor of JIASE

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# Disproportionate Representation of Culturally and Linguistically Diverse Students with Special Needs: An Ongoing Concern

#### John Mouanoutoua

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#### **Abstract**

In the United States, culturally and linguistically diverse (CLD) students with special needs continue to be disproportionately represented in special education. Over the past few decades, federal and state policy changes have reduced the disproportionality, but there remains an alarming impact on these children and their families. This article provides a historical summary of the overrepresentation of CLD students in special education programs, problems that serve as the foundation for the disproportionality, and ongoing efforts to minimize it. Factors that continue to serve as contributors to this disproportionality are identified and discussed. The article ends with a focus on current efforts to address the issue of disproportionality and implications for future progress to reduce the number of CLD students with special needs in special education classrooms.

Keywords: culturally, linguistically, diverse, disproportionality, representation, response to intervention, multi-tier system of supports, teacher preparation

# INTRODUCTION

Culturally and linguistically diverse (CLD) students have been disproportionately represented in special education since the 1960s. In 1968, Dunn reported the overrepresentation of minority students in special education classes for mild intellectual disabilities (ID). According to Dunn, minority students were categorized as nonstandard-English speakers and were usually of low socioeconomic status. At the time, Dunn reported, minority students represented 60-80% of the students in special day classes because of their intellectual disability. After Dunn, Mercer (1973) reported an anomaly in student placements into ID classes for a certain subgroup of students in California. Mercer determined that the number of Mexican American students being placed in special education classes because of their ID was four times their percentage of the population. At the time, Mercer further reported that over half of Mexican American and Black youths 15 years of age and younger obtained failing scores on the intelligence quotient (IQ) test when compared to their White counterparts, regardless of the criterion cutoff point on the test.

It was not until the 1980s that Finn (1982) evaluated special education disproportionality at the national level. Using data provided by the Office of Civil Rights through the United States Department of Education, Finn reported that specific subgroups of students were disproportionately identified in special education. For

example, Native American students were overrepresented in learning disability (LD) classes, and African American students were overrepresented in classes for emotional disturbance (ED) and ID. Asian American students were underrepresented in almost every disability category.

Disproportionate representation in special education is still unresolved and requires immediate attention (Artiles & Bal, 2008; Bal et al., 2014; Donovan & Cross, 2002; Hosp & Reschly, 2004; Skiba et al., 2008). Disproportionate representation is a problem because inaccurate placement of students often renders special education programs ineffective, and it can stigmatize students. Disproportionate representation has occurred because of inequities in educational assessment, identification, and placement of all groups of students (Heller et al., 1982; Patton, 1998). Disproportionality remains a complex, multidimensional problem, and educators and scholars have diligently tried to solve it (Artiles et al., 2010; Klingner et al., 2005; Zhang et al., 2014).

This article describes existing underlying problems identified as possible contributors to the disproportionate representation of CLD students in special education. Moreover, information will be shared detailing how the disproportionate representation of CLD students has been addressed over time. Finally, the implications regarding the impact on current referral, identification, and service delivery practices of specific attempts at addressing the problem will be discussed.

# **METHODS**

Articles for this manuscript were found using online databases such as ERIC and EBSCOhost. Ancestral search was also used once an article of interest was highly relevant to this topic. Keywords used to identify articles of interest consisted of special education, culturally and linguistically diverse, disproportionate representation, and United States of America. Inclusion and exclusion criteria were used to select articles appropriate for this topic. Inclusion criteria consisted of (a) articles that are peer-reviewed, (b) articles focused on public schools in the United States, (c) articles that focus on either culturally or linguistically diverse students with special needs, (d) studies that are qualitative or quantitative, and (e) chapter books relevant to this topic. Exclusion criteria for this manuscript consisted of the opposites of inclusion criteria. Overall, there were more than 100 articles found searching the keywords in the databases. However, after applying the inclusion and exclusion criteria, approximately 44 resources were used to complete this manuscript.

# **Problems Underlying Disproportionality in Special Education**

Three underlying problems have been identified as possibly contributing to the disproportionate representation of CLD students in special education: (a) the use of biased standardized assessments, (b) inequalities in general education, and (c) flaws in the process of determining special education eligibility.

# **Biased Assessments**

When students are being evaluated for special education services, educators may use some form of standardized psychometric test to determine the student's level of intelligence. However, the appropriate use of standardized psychometric tests for students with different cultural backgrounds remains a concern (Lambert et al., 2022). According to Gibson (2022) and Lambert et al. (2022), African American students are overrepresented in special education under the category of emotional disturbance (ED) when psychometric tests are used to assess them for special education services. Standardized psychometric tests that educators use to make eligibility decisions are often biased in measuring intelligence levels (Hosp & Reschly, 2003; Skiba et al., 2008; Zhang et al., 2014). Assessment bias exists if quantitative validity indicators differ for different groups (Jensen, 1980, 1998). A specific test can be analyzed for bias effects by examining its construct validity; conducting an item

analysis may reveal significant "item by group interaction," suggesting that a specific item deviates significantly from the overall profile for any group of students (Donovan & Cross, 2002).

Alternatively, predictive validity can also be used as a potential indicator of assessment bias. It involves correlating measures of intellectual functioning with academic achievement (Donovan & Cross, 2002). For example, Valencia and Suzuki (2000) investigated 32 cases of possible assessment bias and reported concerns of bias related to predictive validity in some of the cases under their review. In 18 cases involving students from culturally or linguistically diverse backgrounds, they ultimately confirmed that 6 exhibited biases through the predictive validity indicator.

Generally, the argument has been that standardized assessments' content, structure, format, or language are biased in favor of students from mainstream or middle-to upper-class backgrounds (Donovan & Cross, 2002). Therefore, when being assessed for special education services, students from culturally and linguistically diverse backgrounds may be at a disadvantage because of preexisting bias that either has been incorporated into the test through the development and selection of items or through the extent to which an intellectual score is compared to their achievement level.

# **Inequalities in General Education**

Another factor contributing to the disproportionate representation of CLD students in special education is the presence of inequalities in general education (Skiba et al., 2008; Zhang et al., 2014). Every student should have an opportunity to learn with the same access to resources that enhance their learning as every other student. However, that ideal is not always the case. Skiba et al. (2008) lamented that inequalities in general education are systemic issues that require systemic changes. For example, curricular and instructional materials used to teach students have been shown to favor mainstream students who are not culturally or linguistically diverse (Ferri & Connor, 2005). In addition, Asian American students with disabilities are more likely to be included in general education classes than their Latinx or white counterparts. In contrast, African American students with disabilities are even less likely to be mainstreamed (Cooc, 2022).

Another example of inequality is the fact that effective teachers often hesitate to teach in challenging schools that are perceived to serve students of color from low socioeconomic status (Darling-Hammond,

2004). Greenwood et al. (1994) observed that schools in low socioeconomic areas provided inferior instruction from less effective teachers that resulted in less academic engagement, equivalent to 57 weeks of lost instructional minutes when compared to schools located in higher socioeconomic neighborhoods. More than a decade after Greenwood et al.'s research, students affected by disproportionality in special education continue to receive less rigorous instruction and less robust curricula (Harry & Klingner, 2006). These studies demonstrate that educational opportunities and systems that are not culturally sensitive towards culturally diverse students can impact their academic achievement, elevating their risk for placement in special education services. Students with disabilities must be taught by effective teachers to ensure that all students can achieve a solid and positive result (Brownell et al., 2023).

# **Eligibility Determination Process**

A third possible factor in the disproportionate identification and placement of CLD students into special education is the special education eligibility and decision-making process (Zhang et al., 2014). Skiba et al. (2008) reported that disparities in special education could be leveraged by inadequacies in practice or bias generated during the special education referral and decision-making stages. In essence, practitioners may sometimes make critical decisions regarding special education eligibility based on their subjective understanding of the law (Hanchon & Allen, 2018). For example, Hosp and Reschly (2003) reported that Latino and African American students had a higher rate of referral to special education than white students. One area for improvement in the decision-making process that may contribute to the disproportionality of culturally diverse students in special education is the difference in the opinions of referring teachers at conferencing (Harry & Klingner, 2006). Furthermore, ongoing research has suggested that CLD students are frequently misidentified as having a disability and thus improperly receive special education services (Haager, 2007; Moreno & Gaytán, 2013; Rinaldi & Samson, 2008). Therefore, the problems with the eligibility and determination process continue to place CLD students at a disadvantage, incorrectly labeling them as special education students.

# **Continuing Efforts to Minimize Disproportionality** in Special Education

Throughout the 1980s and 1990s, the federal government recognized the existence of disproportionality and saw that it may have potential discrimination claims.

This recognition resulted in a monitoring system developed by the U.S. Office for Civil Rights to track the ethnic representation of students in special education (Coutinho & Oswald, 2000). Most noticeably, the National Association of State Directors of Special Education (NASDSE) began policy forums in 1994 to invite and encourage constructive dialogues at a national level regarding the disproportionate representation of cultural minorities in special education (NASDSE, 1994, 1995). As a result of the first forum, in 1994, NASDSE developed action plans to enhance teachers' capacity with diverse learners and improve pre-referral strategies (Coutinho & Oswald, 2000).

Efforts to address the disproportional representation of CLD students in special education have continued at the federal and state levels. The federal government has enacted legislative initiatives that have focused on the disproportional representation of CLD students in special education. The legislation requires cultural and linguistic data collection regarding discipline, graduation, and dropout rates in special education (Zhang et al., 2014). Under the Individuals with Disabilities Education Act (IDEA) of 2004, states must have systems and procedures to prevent disproportionate representation by race, ethnicity, and disabilities. This federal mandate ensures that state systems collect and monitor educational practices and policies to deter the disproportionate representation of CLD students in special education. More specifically, states must (a) review and revise, if necessary, policies and procedures used to identify and place students to ensure compliance with IDEA requirements; (b) maximize the use of funds to provide comprehensive early intervention services; and (c) report any changes of practices, policies, and procedures to the public (IDEA, 2004).

To evaluate the effects of federal mandates, as mentioned previously, Zhang et al. (2014) conducted a study using data provided by the U.S. Census Bureau and IDEA for 2004 through 2008. The study aimed to evaluate longitudinal trends of disproportionate representation in special education. Results suggested that minor changes took place in the five years after the federal mandates went into effect. Of the five racial groups in the study (Alaskan/Native American, Asian/Pacific Islander, African American, Hispanic, and White), the African American group exhibited an essential change in the intellectual disabilities category. The number of African American students in this category showed a significant drop.

# **Current Impact on Referral, Identification, and Service Delivery Practices**

Actions taken to address the disproportionate representation of CLD students in special education have affected the practices used to refer students, identify disabilities, and deliver services. CLD referrals for special education must be grounded in culturally responsive, multi-tiered instructional decision-making (Hoover, 2012; National Center on Response to Intervention, 2011). Often, teachers may need to be culturally competent to make such decisions (Klingner et al., 2005). Several scholars and teacher trainers have proposed developing and sustaining culturally responsive teacher preparation programs that can produce effective teachers who are competent in making decisions about referring CLD students for special education services (Countinho & Oswald, 2000; Dunn, 1968; Hoover & Erickson, 2015; Klingner et al., 2005; Trent et al., 2008). This type of training, in turn, could help states document disproportionality in special education as mandated by IDEA. States with colleges and universities that promote culturally responsive curricula in their teacher preparation programs can produce culturally responsive teachers who can effectively and appropriately make referrals regarding CLD and special education.

Attempts to address the issue have also affected identification and service delivery practices. A significant impact on the identification and service delivery practices regarding CLD and special education is the use of Response to Intervention (RtI) or a multi-tier system of supports (MTSS) framework. Since its formal introduction by IDEA in 2004, RtI has been the most frequently adopted and trusted method of identifying and providing special education services for qualified students; it is rapidly replacing the traditional IQ discrepancy method (Yell & Walker, 2010). The reauthorization of IDEA in 2004 means that states can no longer require school districts to use the IQ discrepancy method to identify students with disabilities (Yell & Walker, 2010). To be a little more specific, section 1414(b)(6)(B) of the reauthorized IDEA (2004) states that local school districts can use a process to determine if a child responds to scientific and research-based interventions as part of the evaluation process. Policymakers supported and recommended using an RtI approach even before scholars and researchers could answer definitive questions about the practice (Scott et al., 2014). For example, the state of Iowa had already been using an RtI approach since 1995, long before IDEA mandated states to use alternative methods for identifying students with disabilities (Ikeda, 2012).

As RtI evolved, so did its sensitivity to the needs of CLD students. Scholars have researched and proposed a RtI model that is more appropriate for and more culturally responsive to the needs of struggling CLD students than earlier models (Klingner et al., 2005; Linan-Thompson et al., 2007; Orosco & Klingner, 2010). For example, the PLUSS RtI model proposed by Sanford et al. (2012) aims to support CLD students by emphasizing the following components: (a) pre-teaching of critical vocabulary, (b) language modeling and provision of opportunities to use academic language, (c) use of visual and graphic organizers, (d) incorporation of systematic and explicit instructions, and (e) strategic use of native language and teaching for transfer. Using a culturally responsive RtI approach to identify and deliver services to CLD students who would benefit from special education can help rectify the disproportionate representation of CLD students in special education.

# CONCLUSION AND RECOMMENDATIONS

To summarize, the disproportionate representation of diverse students with special needs is an ongoing concern (Cooc, 2022; Skiba et al., 2008). Research has identified three factors contributing to this issue and recommendations that can help reduce the disproportionality. The first factor—bias assessment—implicates using standardized psychometric tests when assessing students for special education eligibility. This results in an overrepresentation of African American students being qualified for ED. Research recommends a more holistic approach, such as using a RtI or MTSS framework, to assess diverse students for special education services.

The second factor is the inequality that diverse students with special needs experience in a general education setting. Often, diverse students with special needs are not offered the opportunity to be mainstreamed within the general core curriculum nor given effective special education teachers. The law required that diverse students with special needs be given the least restrictive learning environment, even if that is within a general education setting. Research recommends training pre-service teachers in culturally relevant practices and that in-service teachers continuously use professional development opportunities to stay current on culturally responsive pedagogy (Hoover & Erickson, 2015; Trent et al., 2008).

A third factor contributing to the disproportionality of diverse students in special education is the determination eligibility process conducted by practitioners. Scholars have reported that disparities in special education could be impacted by inadequacies in practice or bias generated during the referral and decision-making stages. Furthermore, practitioners may resort to their subjective understanding of eligibility requirements, thus tainting the determination process. It is recommended that practitioners continuously review federal mandates and regulations when determining student eligibility and, if necessary, ask for assistance from their special education leadership team on a local and state level (Brownell et al., 2021). Furthermore, regional institutions of higher education could provide professional development to support this matter. As legislation is updated on federal, state, and local levels, practitioners should be aware of these updates to avoid bias and inadequacies that might harm their determination of the eligibility process for diverse students.

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# Virtual Intervention to Build Reading Fluency for Struggling Readers in India: A Preliminary Study

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#### **Abstract**

This study examines the effectiveness of a virtual intervention program to improve reading fluency for struggling learners. Grade 3 students in a private school in Mumbai were screened using a curriculum-based measurement application developed for the Indian context. Twenty-eight participants who fell below the 15th percentile on the application participated in a 17-week reading fluency program. Results indicated that there were no statistically significant differences between the treatment group and the control group. However, a closer examination of the results showed that students in the treatment group (a) improved reading fluency scores from pre- to post-test compared to the control group and (b) had fewer errors in fluency with the intervention in place. We also noted that the reading app effectively identified struggling readers in the Indian context and may be considered an appropriate screening and monitoring tool for Indian schools. Implications for reading assessment and intervention in the Indian context will be discussed.

Keywords: Virtual instruction, curriculum-based measures (CBMs), reading fluency, students at-risk, India

# INTRODUCTION

The recent National Education Policy of India (Ministry of Human Resource Development, 2020) aims to achieve foundational literacy for all students by 2025. This is an ambitious goal, given the current situation in India. Before the COVID-19 pandemic began in 2020, reading outcomes for students were of concern, and they have only worsened since. According to the ASER report (ASER Centre, 2023), a status report on reading outcomes in rural India, only 40% of fifth-grade students can read second-grade texts. Another national assessment indicated that less than 50% of students in Grade 3 were proficient in reading (National Council of Educational Research and Training, 2017). These outcomes have been made worse by the COVID-19 pandemic. India had one of the longest lockdowns in the world, with schools remaining closed for physical classes for almost two years in some cities (UNICEF, 2021). One report noted that 92% of students had lost at least one reading skill during the pandemic (Azim Premji Foundation, 2021). The pandemic is over, and schools have reopened, but there is a need to explore how to bridge the gap for learning loss and help students catch up. This paper examines the effectiveness of a virtual strategy to build reading skills for struggling learners.

# **Reading Fluency**

Reading fluency is "the ability to read connected text rapidly, smoothly, effortlessly, and automatically with little conscious attention to the mechanics of reading

such as decoding" (Meyer & Felton, 1999; p. 284). Fluent reading is one of the five essential components of reading (National Reading Panel, 2000) and has strong positive relations to reading comprehension (Fuchs et al., 2001). Studies have demonstrated that reading fluency independently contributes to success in reading, especially for struggling readers, and must be taught explicitly (Chard et al., 2002).

# **Reading Fluency Intervention**

Repeated reading has been shown to benefit students who struggle with fluency (Chard et al., 2002). Students read from a text repeatedly until they build mastery. Teachers can support them by providing a model read and corrective feedback during the reading process. Repeated reading can also be practiced with peers. Typically, a more proficient reader is paired with a struggling reader. The students take turns reading a passage while their partner notes down errors. Multi-component interventions, such as combining fluency with decoding, vocabulary, or comprehension instruction, have also improved reading fluency (Gersten et al., 2020; Stevens et al., 2016).

Typically, intervention for struggling readers is recommended from three to five times a week for between 20 and 40 minutes (Gersten et al., 2008). This includes multiple components of reading, fluency being one of them. Reading fluency interventions are effective in small groups for about 15 minutes daily (Ross & Begeny, 2015). Maki and Hammerschmidt-Snidarich (2022)

examined the role of fluency intervention dosage and found that longer interventions led to more significant student growth.

# **Measuring Reading Fluency**

Reading fluency is typically measured as the number of correct words read in a minute using a curriculum-based measurement (CBM) tool. CBMs are brief, reliable, and valid assessments that assess general literacy or numeracy skills (Deno, 2003). They consist of equivalent measures that can be administered repeatedly and used to monitor progress. CBMs also allow comparison to the norm. Thus, CBM assessment provides data about a child's progress over time and their progress compared to their peers. The most widely used CBM measure is oral reading fluency (ORF), in which a student reads aloud from a passage for one minute (Fuchs et al., 2001; Hasbrouck & Tindal, 2017). The number of correct words read and the student's reading accuracy are recorded at the end of a minute.

# **Reading Fluency in India**

There is limited data on the role of reading fluency in building foundational reading skills for primary-grade students in India. A few studies have explored measuring reading competence using ORF. For example, USAID (RTI International & Pratham Education Foundation, 2018) funded a series of projects to build reading competence across different languages in India, including English. Reading fluency was measured using modified versions of the Early Grade Reading Assessment (EGRA) with 14,370 Grade 2 students. The authors reported low reading fluency rates across all languages, ranging from 0.7 correct words per minute (cwpm) to 35.3 cwpm across treatment groups. In sharp contrast to this finding, Paige and colleagues (2013) noted high reading fluency scores when measuring students' reading fluency using researcher-developed reading passages for a private English-medium school in India. The authors compared the student performance of 193 Grade 3, 5, 7, and 9 students to U.S. norms specified by Hasbrouck and Tindal (2006). They reported a mean score of 73.5 cwpm for Grade 3 students, 130.4 for Grade 5, 152.4 for Grade 7, and 162.4 for Grade 9 students, all of which fell at or above the 50th percentile on U.S. norms. Shenoy and colleagues (2020) also measured reading fluency with U.S.-based assessment tools in six private English-medium schools in India. The authors examined the performance of 1,003 students in low-, medium-, and high-cost schools and compared their performance to U.S. norms. Shenoy

and colleagues noted that whereas students in low- and medium-cost schools performed well below the average on U.S. norms across all reading measures, students in high-income schools performed significantly higher on reading fluency when compared to U.S. norms. With limited data, we do not yet have an accurate picture of how students in India perform in reading fluency or how best to intervene. Therefore, we undertook the following study to address this gap in the research.

We were interested in the following research questions:

- 1. Is there significant growth in English reading fluency among students below benchmark in Grade 3 in the intervention group, as compared to the control group, pre- and post-intervention?
- 2. Do students who received a virtual reading intervention program in Grade 3 remain at risk for reading difficulties post-intervention?
- 3. How does reading fluency improve with repeated reading for the intervention group? What is the change in the number of words read correctly and the number of errors made, pre- and post-intervention?

# **METHODS**

# **Participants and Setting**

This study was conducted virtually. The participants were 28 third-grade students from a private English-medium school in Mumbai, India. The school followed the Maharashtra state board curriculum and served students in lower- and middle-income groups. The school only admitted students whose family members were employees of the school's parent company. Most families were provided housing and lived in and around the school campus. Students either had one or both parents employed in the company, and at least one parent had graduated with a professional degree.

Five Grade 3 English-language teachers participated in the study. Three teachers had a bachelor's degree in education, two had a diploma in education, and their teaching experience ranged from five to 34 years.

All 207 third-grade students completed the Fluency Assessment and Benchmarking for Literacy in Education (FABLe) assessment. We selected students falling below the 15th percentile on the FABLe assessment. A total of 30 students were identified. The study's teachers selected students they worked with to form the intervention group. The remaining students in their reading classes formed the control group. Two students from the

Table 1 Demographics of the Intervention and Control Groups.

	Intervention	Control
Total number of students	12	16
Boys	7	10
Girls	5	6
Age range	9–11 years	9–10 years
Students with an identified disability	None	None

intervention group left school during the study, resulting in 12 students in the intervention group and 16 in the control group. Table 1 presents descriptive data on students and teachers. No student had been identified as having a disability before the intervention.

Students in both the intervention and control groups attended general education English Language Arts (ELA) classes that their school offered. Beyond this, the intervention group only received our reading fluency intervention. In contrast, students in the control group received the following intervention: (a) additional tutoring for one hour, two or three times a week, which included reviewing concepts taught during ELA, grammar skills, and writing skills; and (b) remedial classes for 30 to 45 minutes, two or three times a week. Remediation intervention included phonics, fluency, comprehension, and some perceptual skills.

# **Description of Intervention**

Intervention sessions were conducted one-on-one thrice a week, 10 to 15 minutes daily, for 17 weeks. Repeated reading has been shown to improve fluency (Therrien & Kubina, 2006) and can be done in many ways (Meyer & Felton, 1999). We used a repeated reading intervention strategy that included Cold, Warm, and Hot reads (Erickson et al., 2015; see Figure 1). The Cold read served as a pre-assessment. During the Cold read, students read aloud from a passage for one minute. Teachers listened silently and marked any errors on their copy of the reading passage. If a student hesitated on a word for more than three seconds, teachers prompted the student with the word and marked the word as an error.

The teacher marked the last word read at the end of one minute. The teacher then reviewed errors with the students and guided them as needed. Teacher support included correcting mispronounced words, supporting with semantics or understanding words in context,

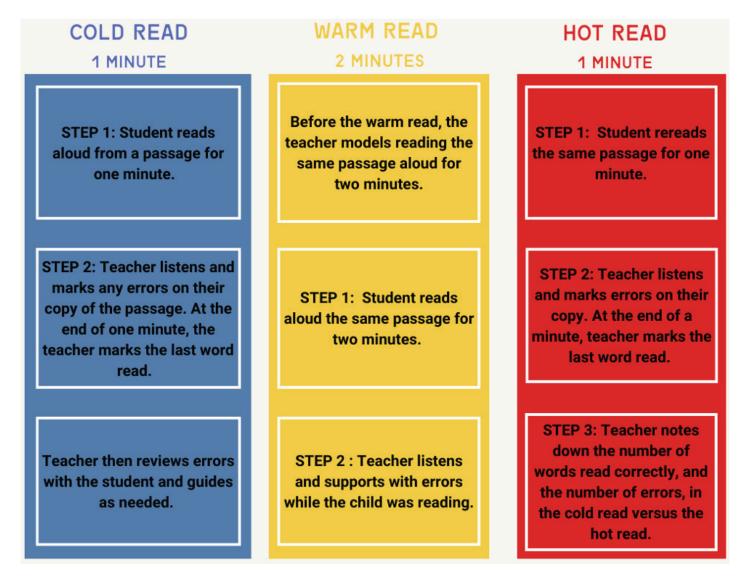
giving mini-lessons on phonics skills, and providing prompts to read fluently. Next, the teacher modeled reading the same passage aloud for two minutes by asking students to focus on how words were pronounced and paying attention to the expressions and intonations used. Next came the Warm read. During the Warm read, students read the same passage aloud for two minutes. Teachers listened and supported them by identifying errors while the student was reading. Finally, the student reread the

same passage in the Hot read for one minute. The Hot read served as a post-assessment. Teachers listened quietly and marked errors on their copy. Teachers marked the last word read at the end of the Hot read. Teachers recorded the number of words read correctly and errors in the Cold read versus the Hot read.

# **Training and Coaching of Teachers**

Participating intervention teachers attended an online workshop before the start of the study and received online bi-weekly coaching sessions for the duration of the study. During the workshop, facilitators modeled how to execute the intervention strategy and record data. Teachers were given opportunities to practice with each other in simulated settings. Teachers then conducted sessions independently and shared recordings with the facilitators. Facilitators viewed the videos and reflected with the teachers at the bi-weekly coaching sessions. The bi-weekly coaching sessions were also used to make data-driven decisions and select reading materials for the coming weeks. For example, at the first meeting, the team determined the grade level at which a student's progress would be monitored. However, if, at subsequent meetings, the team felt a child was progressing too quickly or too slowly at a particular grade level, the progress monitoring grade levels were modified accordingly. Students were monitored at either Grade 2 or Grade 3. The facilitators also worked with the teachers to identify intervention material that teachers felt would be appropriate for the student. Teachers found freely available graded materials particularly helpful, such as those from StoryWeaver (https://storyweaver.org.in/), a site that hosts graded passages designed for the Indian context and made available under the Creative Commons 4.0 license (https://creativecommons.org/licenses/ by/4.0/), and ReadWorks (https://www.readworks.org/).

Figure 1 *Intervention Strategy.* 



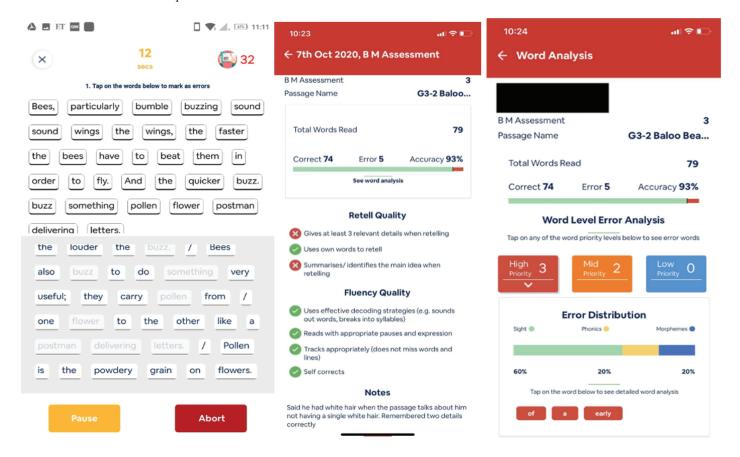
# **Description of Assessment**

This study uses the Fluency Assessment and Benchmarking for Literacy in Education (FABLe) application to measure oral reading fluency. FABLe is the first digital curriculum-based measurement tool developed for the Indian context. Previous studies have established its technical adequacy (Misquitta et al., 2022) and applicability to the Indian education system (Misquitta & Ghosh, 2021). In an FABLe assessment, students read aloud from a text while the teacher follows along on the app and marks errors. FABLe reports the total number of words read, the number of words read correctly, the number of errors, and the accuracy percentage. FABLe also allows teachers to rate students' reading fluency and retell quality. In addition, FABLe includes an error analysis, indicating which errors may be of concern for

the student and the type of error, whether primarily in phonics, sight words, or morphemes. See Figure 2 for sample FABLe assessments and reports.

Online testing was conducted using Google Meets video conferencing software. Students accessed the passages from their homes on desktop computers, laptops, tablets, or phones. The assessors were eight experienced teachers at the research organization. They conducted the assessments using a laptop for a video meeting with the student and a phone or tablet to access the FABLe app. Assessors presented the passage by sharing the screen during the video meeting and monitored student progress on their phones or tablets. All assessors were familiar with conducting fluency assessments using the FABLe app.

Figure 2 FABLe Assessments and Reports.



# RESULTS

This study aimed to introduce teachers to a virtual intervention strategy called Cold, Warm, and Hot reads and examine its effectiveness in improving reading fluency for struggling readers. The results are organized to answer our research questions. Our first research question states:

Is there significant growth in English reading fluency among students below benchmark in Grade 3 in the intervention group, as compared to the control group, pre- and post-intervention?

To answer this question, we used an independent samples t-test at pre- and post-test to compare the means of the control and intervention groups. Table 2 presents the summary statistics for the two groups. We observed no significant effect for correct words per minute for the pre-test scores, t(27)=0.46, p=0.64, despite the control group attaining slightly higher scores than the intervention group (M=29.43, SD=7.79). Moreover, there was no significant effect for errors, t(27)=0.51, t=0.61, despite the intervention group attaining slightly higher scores than the control group (M=6.50, SD=5.74).

Table 2
Summary Statistics of Correct Words Per Minute (CWPM) and Errors for the Intervention and Control Groups.

	Intervention Group (n=12)			Control Group (n=16)				
	Mean	SD	Min	Max	Mean	SD	Min	Max
Pre-test: CWPM	28.16	6.22	16	38	29.43	7.79	17	39
Pre-test: Errors	6.5	5.74	1	22	5.68	2.49	2	9
Post-test: CWPM	37.33	11.17	18	56	36.56	9.41	24	48
Post-test: Errors	4.58	3.20	0	10	4.81	2.58	2	12

For the post-test scores, we observed no significant effect for correct words per minute, t(27)=0.19, p=0.84, despite the intervention group's slightly higher error rate than the control group (M=37.33, SD=11.17). Moreover, there was no significant effect for errors, t(27)=0.21, p=0.83,despite the control group attaining a slightly higher error rate than the intervention group (M=4.81, SD=2.58).

Despite this group result, we noted some individual scores that warranted further analysis, as captured in our other two research questions.

Our second research question states:

Do students who received a virtual reading intervention program in Grade 3 remain at risk for reading difficulties post-intervention?

To answer this question, we looked more closely at the change in percentile ranks from pre- to post-intervention for the control and intervention groups, as presented in Table 3. For the intervention group, we found that two students (16.66%) moved to the 26th and 28th percentile, respectively, indicating they were no longer at risk. Out of the ten students who remained at-risk (below the 15th percentile), a majority (6 students or 60%) showed growth in reading fluency skills, while three students (30%) showed a decline, and one student (10%) remained at the same level. For the control group, on the other hand, we found that six students (37.5%) did not remain at risk. Out of the ten who remained at-risk, three students (30%) showed growth in reading fluency, and seven (70%) showed a decline.

Finally, we were interested in individual-level growth documented for the intervention group. Thus, the third research question states:

Table 3
Percentile Changes from Pre- to Post-Tests for the Intervention and Control Groups.

Intervention Pre-Test Percentile Rank	Intervention Post-Test Percentile Rank	Control Pre-Test Percentile Rank	Control Post-Test Percentile Rank
0	9	1	2
1	3	1	21
5	0	1	16
5	12	2	6
6	5	4	1
7	13	4	3
7	26	6	5
7	10	9	16
8	11	10	13
9	9	10	5
11	3	11	1
14	28	11	18
-	-	11	16
-	-	13	20
-	-	13	8
-	-	15	13

How does reading fluency improve with repeated reading for the intervention group? What is the change in the number of words read correctly and the number of errors made, pre- and post-intervention?

In order to answer this question, we graphed the correct words read per minute and the number of errors recorded for all 12 students in our sample, presented in Figure 3. We observed that irrespective of risk status, that is, whether students remained at risk or were reclassified as not at-risk, they all showed growth in the number of correct words per minute (CWPM) and a decline in the number of errors recorded from the beginning to the end of the intervention period. Teachers also noted that students became more interested in reading, and students who previously did not wish to read were eager to attend the classes.

#### DISCUSSION

The purpose of this paper was to examine the effectiveness of a virtual intervention strategy of Cold, Warm, and Hot Reads to build fluency for struggling learners. To determine the effectiveness of the intervention, we (a) compared the performance of the intervention group to a control group; (b) noted the percentile

Figure 3 *Individual Changes in Correct Words Per Minute (CWPM) and Error Rate for the Intervention Group.* 



Key: Dark Grey=Pre-test and Light Grey=Post-test.

change, if any, in student performance; and (c) compared intra-group performance for the intervention group, pre- and post-intervention.

To begin with, we did not note a statistically significant difference in mean scores between the intervention and control groups. We were curious to understand the reason for this. The study was conducted over 17 weeks. Typically, extensive interventions are conducted over 16 to 24 weeks (Denton et al., 2011; Wanzek & Vaughn, 2007), and ours fell within this range. Second, teachers had submitted video recordings of their intervention sessions, all conducted with fidelity. Therefore, we ruled out the duration of the intervention and fidelity of intervention as possible reasons for not seeing a difference. One reason we postulated could have been the nature of the intervention. The intervention included only reading fluency, excluding other components of reading. Reading is multi-faceted and impacted by several components. Research suggests that multi-component interventions have been effective (Stevens et al., 2016). Thus, the intervention might have needed to be more intensive to bring about a significant change (Vaughn et al., 2010). Future studies could explore a multi-component reading intervention to support struggling learners. A second reason could be that the control group also received some form of intervention from the same teacher. Although not planned for at the start of the study, teachers mentioned they had tried the Cold, Warm, and Hot reads strategy with their remedial groups. Thus, because both groups may have received a similar form of intervention, the effects of the intervention in this study may have been somewhat dampened. Finally, a third reason is that this study had only a limited number of participants and may need more statistical power to detect a significant effect. Future studies could consider more controlled designs with a larger sample size to determine the effectiveness of the intervention strategy.

Although students in the intervention group did not outperform those in the control group, we noticed some positive changes in the intervention group over the control group. When looking at their scores, we noted that students in the intervention group showed more growth in reading fluency compared to the control group, and fewer students in the intervention group showed a decline in reading fluency compared to the control group. Further, when examining each student's pre- and post-test scores, we noted that students in the intervention group had more correct words per minute and fewer errors in their post-test compared to the pre-test. A

second consideration is how fast students with disabilities must read to improve their reading comprehension. Studies suggest that students with disabilities may never achieve the fluency levels of their peers and that this might not be necessary for improving their comprehension (O'Connor, 2018). For example, achieving rates of 90 correct words per minute for fourth graders may be enough to support students' reading comprehension. Therefore, we concluded that the intervention's impact on improving reading fluency for struggling learners warrants further investigation.

Another finding from this study was that our screening tool, FABLe, successfully identified at-risk students in the Indian context. All students falling below the 15th percentile on the FABLe-established benchmark were students the teachers confirmed were struggling with reading and would benefit from additional support. Moreover, most students remained at risk throughout the intervention period, suggesting that some of these reading struggles might be attributed to a disability, warranting further evaluation. Thus, FABLe appears to be an effective screening tool for schools in India and can pinpoint students who need additional support and might be at risk for a disability (Misquitta et al., 2022).

# **Implications for Research**

There is evidence of repeated readings in international contexts, especially regarding teaching students English as a Foreign Language (EFL). With their studies on EFL learners in Vietnam, Taguchi et al. (2006) and Gorsuch and Taguchi (2010) established some early quantitative evidence for the positive effects of repeated readings. More recently, Serrano and Huang (2023) conducted a study on repeated readings with Taiwanese EFL students and found that short-spaced sessions (five sessions on consecutive days) improved vocabulary learning much more than long-spaced sessions (one session per week). Our study is one of only a few studies that measure the role of repeated readings in the Indian context (RTI International & Pratham Education Foundation, 2018; Paige et al., 2013; Shenoy et al., 2020). As a next step, more studies need to be conducted to observe the efficacy of repeated readings in this context and validate our results. Moreover, we selected a group of students who were performing well below the reading benchmark in Grade 3, so as a next step, we would like to extend this study to all students and not only those who might be at risk for reading difficulties to measure the efficacy of the strategy for different types of readers and create more robust comparison groups.

An important observation from this study is that teachers could implement the strategies with fidelity. This has significant implications in countries like India, where resources are scarce, student-teacher ratios are high, and instructional time is limited. In our future work, we plan to extend this strategy to other Indian languages and urban and rural settings. Our professional development (PD) included a knowledge-sharing workshop and bi-weekly coaching sessions. We reviewed video footage and shared feedback, helped problem-solve with teachers, and planned for the upcoming sessions. Such instructional coaching practices (Sims et al., 2021) have been seen to be impactful in PD programs. It would be interesting to understand better which components of our PD contributed to teachers' implementation and if these can be replicated at scale.

Finally, future research can explore how best to identify learners with reading challenges. Fluency is a bridge between decoding and comprehension, the ultimate goal of reading (Pikulski & Chard, 2005). However, relying on fluency alone may only accurately capture some learners who struggle with reading (Dowd & Bartlett, 2019). In our previous work, we noticed that adding accuracy to the mix could better capture teacher-identified struggling readers (Misquitta et al., 2022). Additionally, better fluency only sometimes results in better comprehension. Studies indicate that above a certain threshold, fluency scores are not as strongly correlated with comprehension (Wang et al., 2019). Future research in FABLe will explore how to triangulate fluency, comprehension, and accuracy scores and how well these three data points predict reading struggles.

# **Implications for Practice**

First, repeated readings were an easy strategy for teachers to learn and implement and could be considered in Tier 1 instruction with minimal training. Second, we caution against teachers using repeated readings as a stand-alone intervention strategy to improve reading fluency. Although it is an effective strategy, it must be used with other strategies to provide intensive reading instruction for struggling readers, especially in Tiers 2 and 3 (Stevens et al., 2016). Third, the literacy app FABLe, which was used for this study, can be extended to benchmark and monitor the progress of all students, not just those at risk for reading difficulties (Misquitta et al., 2022).

# **Limitations and Future Directions**

One limitation was that we focused on only one reading fluency intervention. Future studies should focus on other reading areas, such as decoding and comprehension, to provide students with a more holistic intervention in reading. A second limitation was that the remedial teacher was the same across control and intervention groups. She used the strategy a few times with the control group; even though it was inconsistent, like in our intervention group, it might have been a confounding factor in our findings. Therefore, we need more controlled intervention studies with enough participants to validate our results.

#### CONCLUSION

Our study is important because it extends the current literature on reading fluency intervention in India and adds to our understanding of virtual interventions in this context. Our study is one of the few on reading instructional practices in the Global South. This is a pertinent contribution and begins the dialogue of how reading can be taught in diverse contexts.

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# Exploring the Challenges and Strategies for Saudi Mothers of Children with Autism: An Autoethnography and Interpretative Phenomenological Analysis

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#### **Abstract**

The purpose of this autoethnography and interpretative phenomenological analysis (IPA) study was to gain a better understanding of the challenges faced by mothers of children with autism spectrum disorder (ASD) in Saudi Arabia and the strategies they use to address these challenges. The study focused on Saudi mothers of children with ASD to align with my lived experience as a researcher and full member of this community. This study used my autoethnography writing as a mother of a child with ASD and online interviews with two co-participants (Saudi mothers) raising a child with ASD. The results indicated that the challenges faced by families of children with ASD in Saudi Arabia are ignorance, feelings of guilt, fear, anxiety, diminished social relationships, and lack of services. The results also revealed effective strategies to confront these challenges: accepting reality, assuming responsibility, and looking for distractions through stress-relieving activities.

Keywords: autism, challenge, strategy, mother, Saudi Arabia

# INTRODUCTION

Over the past 15 years that I have lived with a child with autism spectrum disorder (ASD), I have learned many things about ASD. Among them, ASD is a term used for a group of neurodevelopmental disorders characterized by difficulties in social interaction, difficulties in language communication, and repetitive behaviors (Faras et al., 2010). Having a child with ASD leads parents to face many challenges that can taint marital relationships and sibling relationships (Papadopoulos, 2021). Families of children with ASD often feel anxiety and guilt, so they need support and help (Catalano et al., 2018). The need for support and assistance is consistent among many families across the globe. It is essential when exploring the experiences of mothers in Saudi Arabia. There is extensive research on the challenges facing families of children with ASD in Western countries (Vernhet et al., 2019). However, there is limited research exploring how Saudi families of children with ASD overcome these challenges (Balubaid & Sahab, 2017).

# ASD Knowledge and Supports in Western vs. Middle Eastern Countries

According to Alkhalifah and Aldhalaan (2018), ASD is among the most widespread forms of developmental disability. Alenazi and colleagues (2020) state that the Gulf countries (Bahrain, Kuwait, Oman, Qatar, Saudi Arabia, and the United Arab Emirates) have an ASD

prevalence of 29 per 1000 persons, which is relatively low compared to the United States (U.S.). The lower prevalence of ASD in Gulf countries is likely caused by limited awareness and research on ASD in those countries (Alenazi et al., 2020). ASD prevalence statistics in Saudi Arabia are unavailable, and researchers believe this is related to the country's limited awareness and research (Alkhalifah & Aldhalaan, 2018).

The methods developed in Western countries to provide support for people with ASD have significantly improved the health and lives of individuals with ASD in the West. However, people in Saudi Arabia have been forced to travel abroad to seek such services because individuals with ASD are held culturally unsuitable in the country. For example, many families in Saudi Arabia go to Jordan, a neighboring country, to seek special care for their children with ASD (Alkhalifah & Aldhalaan, 2018).

Over the years, the government of Saudi Arabia, through the education and health sectors, has established several interventions to support children with ASD (Alkhalifah & Aldhalaan, 2018). For instance, the government supports and helps to fund private institutions that provide care for children with ASD. The government offers specialized education and has established several healthcare centers treating ASD. However, individuals with ASD still receive most of their care from family members; thus, their parents face multiple challenges (Al rubiyea, 2010).

# Saudi Families' Challenges and Strategies

When exploring the literature surrounding families' reported challenges and strategies related to raising a child with ASD in Saudi, there are many similarities to families' experiences in the U.S. Many families raising a child with ASD report depression, stress, fear, and anxiety, regardless of the location (Asi, 2016; Balubaid & Sahab, 2017; Coleman et al., 2023; Hemdi & Daley, 2017; McAuliffe et al., 2017; Sahab & Balubaid, 2017). However, cultural differences influence why families report this stress.

# Saudi Society, Culture, and ASD

Saudi culture and traditions, Islamic religious beliefs, and Saudi education laws affect parents of children with ASD and increase the challenges they face in Saudi society. In Saudi society, the husband and wife traditionally live in the home of the husband's family after marriage and the birth of children (Al rubiyea, 2010). Al rubiyea (2010) explains how these traditions can hinder the parents of children with ASD. (1) Family members who live in the house (e.g., grandparents, uncles, aunts) provide little support, yet they interfere in raising the child with ASD despite their inexperience with autism; thus, there is no one whom parents can rely on. (2) Saudi wives are the primary caregivers for their children, husbands, and extended family members, so they cannot adequately care for all family members and a child with ASD. (3) Saudi culture blames the mother and holds her responsible for the child with ASD. Many people place blame because they think the mother did not care about healthy nutrition during pregnancy and neglected the child after birth. Therefore, Saudi mothers feel they have failed as mothers and wives (Al-Towairqi et al., 2015).

Islamic religious beliefs also affect Saudi families' information about ASD. Many Muslim mothers believe that black magic is the cause of ASD, so they waste their money, effort, and time on ineffective treatments (Algahtani, 2012). These beliefs and misinformation spread quickly because of the reliance on social media to receive information about ASD (Al-zaalah, 2015).

# **Limited Services**

Fortunately, the educational services provided by the Saudi government are free for Saudi children with ASD, but access to these services is limited (Alamri & Tyler-Wood, 2016). These services are concentrated in the major cities, and they have long waiting lists and complex admission requirements and only serve children with severe and moderate ASD under the age of 13 (Alamri & Tyler-Wood, 2016). Therefore, many parents

pay to educate their children in profit centers that the government does not fund. This puts a heavy financial burden on families and contributes to the reported challenges.

# **Limited Reported Strategies**

We have some information about parents' views about the ASD diagnosis, interventions, and education for children with ASD in Saudi Arabia. However, the Saudi literature contains limited lived experiences of mothers of children with ASD and the challenges they face (Khan et al., 2020). Further, families use limited research reporting strategies to overcome the difficulties reported (see the systematic literature review reported in Aljuaid [2023]).

Balubaid and Sahab (2017) interviewed eight parents (mothers: n = 6, fathers: n = 2) and found that the strategies that helped raise a child with ASD included spirituality, social media, and in-home help (e.g., paid maids). Alqahtani (2012) reported that only one participant in their study (total n not provided) reported using a casein- and gluten-free diet to raise their child with ASD. The parents said these strategies reduced stress; however, it is concerning that some of these strategies are not evidence-based and could be harmful. For example, if parents rely on social media for support, they could begin believing the myths and misinformation circulating. Al-zaalah (2015) explains that there is very little reliable information about ASD in Saudi Arabia, as Saudi families typically receive information about ASD from publications on social media (e.g., X, Facebook) written by people who are not ASD specialists. Further, Mulloy et al. (2010) explain that there is little evidence to support the use of diets to treat ASD. The researcher further states that gluten- and/or casein-free diets should only be used to treat a confirmed gluten and/or casein allergy.

# **Purpose of the Study and Research Questions**

The purpose of this autoethnography and interpretative phenomenological analysis (IPA) study is to gain a better understanding of the challenges faced by families of children with ASD in Saudi Arabia and the strategies they use to address these challenges. Parents and workers in the ASD field will benefit greatly from learning more about this topic. A better understanding of these issues will also be essential as ASD diagnosis continues to rise. Parents also need strategies and guidance from formal and informal sources on how to raise children with ASD so they can focus on their children's development. The following two research questions guided this study: (1) What are the main challenges

facing Saudi mothers of children with ASD? (2) What are the strategies they use to address these challenges? As recommended in an autoethnography (Wall, 2008), I will first present my story as a Saudi mother of a child with ASD. I then report the information I gathered from other mothers' experiences.

# Autoethnography

I, Mashael, the first author, lived most of my life in Saudi Arabia and recently moved to the United States to further my education. I am the mother of a 15-year-old child with autism spectrum disorder (ASD). His name is Azoz and he is the second child in my family of three boys and one girl. After getting married, I moved with my husband to another city. It was the first time I had been separated from my birth family. I lived with my husband's family in their house. Azoz's birth was complicated compared to his older brother. The birth did not leave physical problems but left me with psychological issues. I suffered from panic attacks and fear for several months after birth, but I did not visit a psychiatrist for fear that my husband and his family would believe I was suffering from insanity. After seven months, I found some information online for relieving psychological pain, such as exercising and eating healthy foods. I used this information and started to feel better.

Six months later, I noticed that my son was different from his older brother, as he did not respond to his name, did not use his eyes to communicate with those around him, and did not care about the presence of other children. When I talked to my husband, one of my family members, or my husband's family about what I observed about my son, no one listened to me. They said that what I was thinking of was just delusions, that every child was different, and that it was not correct to compare my son with his brother or any other child.

# Lack of Diagnosis and Support

My first pediatrician visit occurred when Azoz was 14 months old. I told the doctor about my fears and doubts and that I felt my child was abnormal. I told the doctor that Azoz's only word was *Mama*. The doctor looked at my son and gave him a pen. When my son held the pen, the doctor said, "Look, your son responds, do not worry. If the child utters a word, he will utter the rest of the words; your son needs only time." The doctor's words did not convince me. I felt he did not have enough knowledge about my son's issue, so I started searching online for a reason for my son's symptoms. I read about ASD and found that most of the characteristics of children with ASD applied to my son. However, I did not know what ASD was. There was no social awareness of

this disorder at that time in my society. Unfortunately, Saudi Arabian culture and the Saudis' lack of awareness about ASD interfered with my son getting a diagnosis and early intervention.

Initially, I was shocked, but I tried to be strong to help my child. I approached my husband about finding a suitable doctor to help us diagnose and treat our son's condition. However, I was surprised by my husband's reaction. He refused to accept that his son had ASD. He asked me to hide the issue from his family and everyone around us, even if it was true. He told me that if his family knew that he had a child with a disability, they might seek divorce for fear of having other children with disabilities. A person with a disability was not welcome in his family because it would damage the marriage prospects of his brothers and sisters, as people might think that the disability was inherited; no one would want to marry into the family. The norms, traditions, and culture of the community were the first challenges that I faced as a mother of a child with ASD in Saudi society. For years, I remained silent about my son's condition due to the stigma of having a child with a disability and the fear of divorce. A woman's divorce harms both her and his family.

# Advocating for Disappointing Services

In 2008, I got a scholarship to study in the United States. My son was almost two years old at the time. I was thrilled, not only because I would achieve my dream and get my master's degree from a developed country, but because I read that the diagnostic and educational services for children with ASD in the U.S. were free and of high quality. I traveled to America, and I did not tell anyone in Saudi Arabia that my son had ASD. After four years in the U.S., I thought my son would become like an average child when he returned to Saudi Arabia. When my scholarship ended and I returned to Saudi Arabia, I was disappointed because my son was only slightly better. I realized that everyone would know my son had ASD because my son was now six years old and still did not speak, nor could he perform simple tasks that other children his age did, such as using the bathroom, changing his clothes, or even feeding himself. This time, though, I felt stronger. I had earned a master's degree in special education and trained in American schools where there were all levels of disability among different ages of children with ASD. I felt I could help my son and build community awareness of ASD. Unfortunately, when I returned to Saudi Arabia, I was shocked that those around me would not help. They blamed me and told lies about my family and myself.

They said that they searched my family history and found that ASD ran in my family. Some even called me a bad person and said God had punished me with this child.

At the beginning of 2012, after my return from America, I went to a public school that would provide services for children with ASD, but they refused to accept my son because he still could not use the bathroom independently. However, I did not give up.

I went to the Education Department in my city and told them what happened. I told them that my son was a Saudi child and that he had the right to receive education according to the special education laws enacted by Saudi Arabia in 2001 (Regulations of Special Education Programs and Institutes, Alnemary et al., 2017). The workers in the education administration agreed with what I said, so they contacted the school to accept my son. However, the school refused for the second time because of crowding and financial pressure on the school since it was the only school funded by the government and providing free services in the city. They put me on a six-month waiting list. After six months, they contacted me and told me that my son could start the next week, but they would only allow him to attend for one semester unless he began to use the bathroom independently. Unfortunately, the classroom environment was not prepared for a child with ASD. For example, they did not provide evidence-based practices (Steinbrenner et al., 2020), such as visual aids, that would help him. After six months, he had not learned to use the bathroom and was expelled.

After this disappointment, I took out a bank loan to send my son to the neighboring Arab country of Jordan, which had a reputation for providing effective special education services. I left him in a residential school as I could not stay with him due to my work obligations. My son stayed for two months, but I could not keep him there longer because of the ill-treatment he received. For example, the specialists working in the center blocked my son's nose to force him to open his mouth to feed him. As soon as we returned from Jordan, Azoz began studying at a center in Saudi Arabia that required us to pay annual fees. Azoz studied at this center until 2018.

# My Motivation for this Study

In 2018, when Azoz was 11 years old, I received a scholarship from a Saudi university to study for a doctorate in America. My son is now receiving good services in American schools, but I cannot stop thinking about what I will do after my scholarship ends two years from now and I return to my country. How will my son complete his education in my country, which has a law that does not allow children with ASD who are over 13 years old to attend school? I share this personal story to explain part of my motivation for pursuing this study.

My interest in this study was shaped by the desire to find strategies to help other Saudi mothers of children with ASD face the same challenges I faced. After reading several published studies, I wondered about the challenges and experiences of these mothers. Where did they get the information they needed? How did they face these challenges? To answer these questions, I wanted to hear stories from Saudi mothers who had experience caring for a child with ASD. This study gives a voice to Saudi mothers of children with ASD so that their experiences and challenges can be better known and understood. Through this study, we will also explore coping strategies in hopes that other mothers and professionals can learn from these experiences and better support each other.

#### **METHODS**

# **Research Design**

This study combines two methodologies, autoethnography and interpretative phenomenological analysis (IPA), and is framed in the IPA approach. I chose to use autoethnography methods to share my story of caring for my child with ASD, the challenges I faced during my journey, and how I overcame them. Autoethnography is a type of qualitative research that allows the writer to use self-reflection on personal experiences and stories and then link their autobiography with broader cultural, social, and political contexts (Wall, 2008). IPA is committed to systematically exploring personal experience (Tomkins, 2017). Using the IPA approach, I explored the lived experience of Saudi mothers of children with ASD, how they understand their situation as mothers of ASD, and how they draw meaning from that understanding. The participants' narration of their real-life stories, combined with the autoethnographic and IPA designs in this study, may illustrate important events compared to other qualitative research designs.

# **Data Collection**

Data were collected from my experiences as a mother of a child with ASD and from recorded online interviews (an initial and a follow-up) conducted with two Saudi mothers of children with ASD. The authors first obtained the approvals of the Ethics Committees at the U.S. university and the Ministry of Education in Saudi

Arabia. I, the first author, then recruited participants by posting information about the study in a WhatsApp group for Saudi parents who had children with ASD. Interested parents sent a private message on WhatsApp expressing their willingness to participate. The first two to contact me were chosen for participation to support the first author's autoethnography writing and to pilot the interview procedures for a future study that would involve a more significant number of participants.

After selecting two parents, I arranged a suitable time for an online Zoom interview with each participant. Consistent with the ethics committee's standards, I provided information about myself, the purpose of the study, any anticipated positive results (e.g., helping Saudi parents and professionals understand mothers' experiences), and possible risks from the interview (e.g., confidentiality risks and discussing topics that might be difficult to speak about). Also, I informed them that their participation was voluntary, that the interview would be recorded, and that all information would be kept confidential and stored in a university-approved cloud-based storage. I obtained the participants' verbal consent to these conditions.

I have a deep personal understanding of the phenomenon and can speak to the participants in this study in their native language, Arabic. Thus, I interviewed Saudi mothers of children with ASD. Each initial interview lasted one to two hours, and follow-up interviews were conducted with both mothers for 30 minutes per interview.

# **Interview Protocol**

The interview protocol used in this study was adapted from Gobrial (2018), my experiences writing my journal entries and autoethnography, and the reviewed literature (Aljuaid, 2023). The second author and I examined, modified, and added questions to the protocol utilized by Gobrial (2018) to suit the purpose and location of this study. Then, the revised interview protocol was shared with a qualitative expert with extensive experience interviewing international participants. After discussing the matter, we added several follow-up questions/probes to understand the mothers' experiences better. I then translated the questions into Arabic. To ensure the accuracy of the transcription, an Arabic-speaking doctoral student independently transcribed the questions as well. The two transcriptions were compared and deemed consistent.

The interview questions were open-ended to allow participants to explain in depth the challenges they faced while raising a child with ASD and the strategies

they used. The interview questions covered seven primary areas, including (1) the child's early years (2) the impact of ASD on the family, (3) milestones in developing the diagnosis, (4) the child's school, (5) the child's behavior and mental health, (6) the child's social life, and (7) the mothers' life and mental health. Based on the literature and my personal experiences, we believed that family members would affect the mothers' experiences; thus, the interview protocol included the question: "What is the reaction of family members when they learn that your child has ASD?" with probes that included: "Do they blame you for that? Do they support you and your child?" In connection with previous literature (Balubaid & Sahab, 2017), Saudi culture, religion, and beliefs in widespread myths are the external environmental factors that significantly impact the child and his or her family. Thus, another interview question example included: "What is your understanding of the causes and nature of autism?" or "Have you been pressed to take up unscientific or unhelpful treatments to 'cure' your child? Can you tell me about those?" (see full interview protocol in Aljuaid [2023]).

# **Data Analysis**

Ary et al. (2018) describe the model used in this study to analyze the interview data. This model contains three clear and comprehensive stages: (1) organizing and familiarizing, (2) coding and reducing, and (3) interpreting and representing.

# Organizing and Familiarizing

After collecting data from the two interview participants and myself, a backup copy of the recorded interviews was made to prevent the risk of damaged or lost content. After that, I transcribed the recordings by hand due to the lack of computer programs that convert Arabic audio content into written text. The written content was reviewed and compared with the original content in the audio recording. Then, the interview transcripts were entered into MAXQDA software to facilitate memo-taking and coding (Ary et al., 2018). The memos I wrote consisted of thoughts about the collected data, plans for the study, and any discoveries or noteworthy findings. I also used a field note log to record my observations, thoughts, feelings, and experiences during and about the interviews and the research process. In these memos, I wrote my comments and questions about the data collected from the participants to help code that data later.

# Coding and Reducing

After writing the memos, I used inductive coding (Creswell, 2013). For example, I began to code the data based on personal comments and questions I wrote in the memos. I read and re-read the data line by line. The data were divided into pieces of information (sentences), and labels were placed on those pieces of information. Then, those pieces were linked with codes. The coding and data were revised again to generate final codes. After all data was coded, similar codes were combined to identify themes (Ary et al., 2018).

# Interpreting and Representing

I interpreted the data by looking at the similarities, differences, and relationships between the participants and my perspectives regarding the challenges and strategies experienced while raising a child with ASD in Saudi Arabia. My interpretations were linked to themes, and illuminative quotes were used to illustrate important themes. In the findings section of this study, the themes and subthemes are presented narratively instead of via tables to stay closer to traditional autoethnography (Ary et al., 2018).

# **Trustworthiness**

Trustworthiness in qualitative research refers to the quality and rigor of conducting research and reporting data by ensuring credibility, dependability, and generalization (Le Roux, 2017). This study achieved trustworthiness through member checking, peer debriefing, and an audit trail.

Lincoln and Guba (1985) recommended member checking to enhance accuracy in qualitative research. This study used two forms of member checking. First, I sent the transcripts to the participants to check the accuracy of the transcription. One of the participants replied that I had accurately interpreted what she said. After analyzing the data and presenting the interpreted findings, I conducted a follow-up interview with the participants. I did this to ensure that I understood what was said. To complete the peer debriefing, I followed the recommendations of Lincoln and Guba (1985). I had an expert in qualitative research who also speaks and understands Arabic. I read the three Arabic interview transcripts (mine and the two participants') and reviewed my analysis to check the compatibility in identifying themes and subthemes. After the expert review and consensus were achieved, we finalized the themes and subthemes. The findings were combined into four main themes. Lastly, throughout the data analysis process, I used an audit trail strategy that clearly described my steps to manage threats to trustworthiness.

# **FINDINGS**

# **Background and Demographics**

#### Mashael and Azoz

I, Mashael, am the first participant. I am 43 years old. I work as a lecturer at a Saudi university, though I am currently on a scholarship to obtain a doctorate in special education from an American university. I have three sons and a daughter. All are in good health and do not have disabilities, except for my second son, Azoz, who is 15 years old. After Azoz's birth, I completed my master's degree and pursued a doctorate in special education that focused on ASD to help my son. Azoz is a tall, thin child because he is selective with food. He was diagnosed with ASD when he was four years old. He was diagnosed with an intellectual disability at the age of 12 by a specialized team at a school for children with ASD that he attended in the U.S. when he moved with me to the U.S., where I obtained my Ph.D. Azoz needs substantial support in many daily tasks.

Azoz is non-verbal, has difficulty sleeping, and has difficulty changing routines. He is not toilet trained. He depends entirely on me to shower and prepare food, but he can dress and undress himself. He can feed himself food that can be eaten with his fingers, but he cannot use a fork or knife. Azoz was born in Saudi Arabia and spent eight years there. Then, he moved with me to the United States and spent seven years in the U.S. During these years in the U.S., he received occupational and physical therapy and educational services. Azoz does not take any medicine. He takes some vitamins, such as melatonin, to alleviate his sleep problems.

# **Amal and Sara**

Amal is 45 and attending school to complete her high school degree. She spent her life raising her children and did not complete her education until after her children grew up. Amal has been living in a small city in Saudi Arabia since she was married 32 years ago. Her socioeconomic level allows her not to need to work outside the home. Amal was eager to help other mothers of children with ASD by providing all the details she could remember about her experiences caring for a child with ASD. She is very knowledgeable about the field of ASD and is keen to attend workshops and seminars that are aimed at raising awareness of ASD. Amal's youngest child is Sara, who has ASD. Amal also has three sons and two daughters; they do not have disabilities. Before Sara's father died, he did not spend much time with the family because he had a second wife and children from the second wife (a common practice in Saudi culture).

Sara was born in 2010; she was 12 years old at the time of the interview. She was diagnosed with ASD by a neurologist in Saudi Arabia when she was three years old. When Sara was eight years old, she and her mother traveled to Jordan for a re-diagnosis because Amal was not convinced that her daughter had ASD. At this time, Sara was re-diagnosed with an intellectual disability and ASD.

#### Nora and Hana

Nora is 43 years old and is a high school physics teacher. She formerly lived in a Saudi village, then moved to a major city when her daughter with ASD, Hana, was born. Nora already had seven children, all of whom are in good health. She is unhappy that her full-time job as a teacher does not allow her to spend more time with her daughter. Nora has much knowledge about ASD through research in articles. She plans to hire a private at-home after-school teacher for her daughter because Hana receives inadequate services.

Hana is 10 years old. She fears sounds and does not want to play with other children. She does not make eye contact with others and cannot communicate verbally. Hana was diagnosed with intellectual disability at age six, but her mother was not convinced of the diagnosis. Hana was re-diagnosed when she was seven years old, and the second doctor told Nora that Hana had ASD and attention-deficit/hyperactivity disorder (ADHD). Nora believes Hana's diagnosis is "mild." Hana takes medicine to reduce hyperactivity and to help her calm down and focus. Hana currently receives speech and occupational therapy sessions. Hana is trained to use the bathroom. She is not selective in food but needs assistance in preparing food.

#### Themes

This section includes themes obtained from the analysis of interview transcripts. The participants and I have a history of challenges and different individual circumstances while raising a child with ASD. We also discussed different coping strategies, such as distraction and acceptance. I group the challenges that I and the other two mothers faced into six main themes: ignorance, feelings of guilt, fear, anxiety, diminished social relationships, and lack of services.

# **Ignorance**

The biggest challenge that these mothers and I faced in raising a child with ASD, which was discussed in detail, was our "ignorance" (stated by Amal) of ASD and ignorance of our rights as parents and our children's

rights. This ignorance of ASD made it easy for us to believe the widespread myths about ASD in our Saudi society. The ignorance theme had some sub-themes, including ignorance of ASD, ignorance of the rights of children with ASD and their parents, and belief in myths.

# Ignorance of ASD

This was one of the challenges we all faced because available information on ASD was scarce, with few studies and research conducted in Saudi Arabia. For example, Nora reported that her ignorance of ASD and its treatments led to a delay in intervention and use of the appropriate medication for her daughter's condition. Nora did not begin the medicine because "I had heard from mothers that it made the child lazy and sleep for long periods, and when it is cut off, it may cause problems for the child such as anger, screaming, and lack of sleep." Ignorance of ASD and its characteristics leads to a prolonged period of denial, as happened with Amal. She disbelieved the diagnosis in the beginning and was ignorant of what ASD exactly meant. She thought her daughter would become normal when she grew up and would no longer need any treatment or intervention. She described:

I did not believe it and said maybe the doctor misdiagnosed Sara. I was ignorant and did not know anything about ASD. One of the doctors who diagnosed her told me that my daughter would not marry. I was surprised how a psychologist would say something like that to the families of children with ASD—instead of raising my awareness, she intimidated me. I was thinking that a child with ASD would become normal over time. I thought the child with ASD was just not wanting to communicate with others, and I think most people in Saudi Arabia still think that. (Amal)

I also reflected that my lack of awareness about ASD affected my son getting a diagnosis and early intervention. When I talked to my husband or, one of my family members, or my husband's family members, about what I observed about my son, no one listened to me. They said I was delusional and that every child was different.

# Ignorance of the Rights of Children with ASD and their Parents

Another challenge that Amal faced was ignorance of her rights. Amal preferred that her daughter study in inclusive schools. She believed that her daughter's disorder was mild and that her placement in inclusive schools would improve her daughter's social communication skills. However, because Amal did not know she had the right to dispute her daughter's placement, Sara, due to her low IQ, was transferred to a segregated school for students with "severe" intellectual disabilities.

A specialist from the Ministry of Education made an IQ test for Sara and gave her a low IQ score. I asked her, "Why? This is a very low score and does not represent my daughter's intelligence." The specialist said, "I'm sorry, but I am forced to put this score." Based on this assessment, my daughter was transferred from the inclusive school to a center for intellectual disabilities. I did not know that I had the right to refuse. My daughter fell behind a school year because of the ignorance of my rights. Instead of being in sixth grade now, she is in fifth grade. (Amal)

# Beliefs in Myths

Ignorance of ASD may lead to believing or following myths, which harms mother and child. The data includes many descriptions of this. I, Mashael, believed the myth that vaccinations cause ASD, so I stopped vaccinating my son against dangerous diseases such as polio and measles. Amal also believed a myth about ASD; she stated:

In fact, there is a myth that ASD is a jinni [a type of harmful spirit]. Sometimes, because ASD is a mysterious disorder and I still don't know much about it, I feel that it is true because my daughter sometimes knows things that I did not tell her or knows what will happen in the future. I took her to a man who read the Qur'an to children with ASD to expel any jinn. I could not continue because I could not tolerate it, and I felt tired and afraid, so I left the place. (Amal)

# Feelings of Guilt, Fear, and Anxiety

The mothers in this study, including myself, feel fear and anxiety. We worry about our children's future, stress, and the pressure they face from family and friends.

# Worries about the Child's Future

We all acknowledged that services for children with ASD were improving, but we worry about what might happen when our children with ASD become adults. Amal and Nora were particularly concerned about the possibility of their children living independently and whether they would have access to employment opportunities. Amal and Nora were also afraid that their children would not receive care if a parent died or became too old to provide care. Amal said:

I am very worried about my daughter's future. I cannot depend on anyone to take care of her. I hope she will be able to live independently. For example, I had to leave the house for five days and leave my daughter with her older sister and the maid. During the five days, she did not shower, change her clothes, or comb her hair. I feel that no one cares about her. (Amal)

On the other hand, Nora could not rely on anyone to help care for her daughter while she was busy. She worries about her daughter's future; she wants her to learn and master daily living skills and learn a profession that would make her financially independent in the future. Nora stated:

I am afraid for her future and how she would depend on herself. I do not want her to be a burden to anyone. I feel sad sometimes because I must leave her with her brothers while I sleep or work. I feel they do not know how to deal with her as I do. (Nora)

#### Stress

Amal and I suffered from stress. For example, Amal is stressed because she cannot enjoy her time, stating:

I cannot travel or leave home for several days. I wish I could go somewhere alone for several days to relax and be cut off from the world. Sometimes, I feel anxious and want to go into a coma so as not to feel sad and stressed. (Amal)

In my autoethnography writing, I also reflected that I felt stressed when my husband asked me to hide our son's disability from his family because they might ask him to divorce me. After all, the presence of a disabled child might damage his siblings' marriage opportunities.

# Pressure from Family and Friends

Nora and I reported that one of the challenges we faced was pressure from friends and family to use treatments whose effectiveness had not been proven scientifically and might even harm the child with ASD. For example, Nora and I were both told to give our children camel milk. We did not want to do this because it harms the baby and may cause digestive problems for the baby (Aldabas, 2015). Friends also pressured Nora to leave her job to devote herself to raising a child with ASD.

Some friends pressure me to quit my job and devote myself to serving and teaching my daughter because there are cases that have improved when the mother empties for her child. (Nora)

# **Diminished Social Relationships**

All three of us expressed sadness for the lack of acceptance of the different behaviors of our children with ASD by friends and family, and sometimes even our children's father. This led to reduced participation in social events, making us feel isolated and lonely. Nora said:

With Hana's presence in my life, I became more withdrawn because she doesn't like to play with others and is disturbed by loud noises, which affect her and make her angry. Also, I avoided visiting my family because I feared my daughter would bite them when angry. (Nora)

Amal also expressed her unwillingness to visit her family and friends:

I do not like visiting family and friends who blame me and accuse me of neglect. They say that I am the cause of my daughter's ASD because I depended on the maid to take care of my daughter, and perhaps the maid had done black magic with the child because of my neglect. Even my husband said that my daughter had ASD because I did not take care of her. I started to feel that I was the reason for my daughter's ASD, which made me isolated from others. (Amal)

I stated in my autoethnography writing that I also withdrew from society when relatives blamed me for my son's condition. Some people even called me a bad person whom God had punished with this child.

# **Lack of Services**

The mothers in this study stated that there is a lack of diagnostic services (e.g., no specialists or precise tools in diagnosis) and a lack of educational services provided to children with ASD (e.g., unqualified teachers and inappropriate curricula).

# Diagnostic Services

Amal and I reported a need for diagnostic services. For example, there are no specialists to conduct the diagnosis and no clear and specific tools for all diagnosis specialists to follow. Amal was dissatisfied with the diagnosis of a doctor in Saudi Arabia, which forced her to travel to another country to re-diagnose. She said:

My daughter was diagnosed with autism in Saudi Arabia by a neurologist, but I was not convinced of the diagnosis because I felt that my daughter had another disability. I traveled to Jordan with my daughter for a re-diagnosis. The Jordanian doctor said that there are seven characteristics of autism and that my daughter has only one trait, and it is not scientifically proven. (Amal)

I stated in my autoethnography writing that the doctor did not run any formal tests or diagnostic tools when I visited him to diagnose my son.

# **Educational Services**

Nora and I reported that one of the challenges we faced in raising a child with ASD in Saudi Arabia was the lack of appropriate educational services. Nora found a lack of qualified teachers in the field of ASD; curricula were not modified to suit the abilities of children with ASD, and classrooms in public schools were not equipped with the tools and resources that children with ASD need. Nora said:

There are no specialist teachers to deal with children with ASD, and the curricula are not modified to meet their needs. In addition to the lack of awareness of teachers and regular students about ASD, even the classrooms are not equipped with tools that serve children with ASD, so I did not feel that my daughter was welcome in the inclusion environment. (Nora)

I faced the same challenge of lack of educational services when the only public school in my city refused to accept my son, which forced me to send him to school in Jordan to receive special education services.

# **Coping Strategies**

After forming a general picture of the challenges the participants faced in raising a child with ASD, the question remained: How did we overcome those challenges? We all provided examples of how we did this. The central theme was adaptation strategies. There were also two subthemes: distraction and acceptance.

#### Distractions

All the mothers in this study were the primary caregivers for their children with ASD. They affirmed their love and devotion to caring for their children and reported that they did not trust anyone else to help them. As a result, they felt physically and psychologically exhausted. Nevertheless, Amal and I decided to rely on distraction activities. These activities helped us maintain our mental health by relieving stress and distracting ourselves from our day-to-day mothering duties. Amal distracted herself with studying and reading:

I am trying to relax, so I am engaging in reading. For example, I read the Qur'an and ask God for help. I also read historical stories and books to relieve stress. Also, I am completing my education after a 25-year hiatus and am now in my last year of high school. (Amal)

I also keep my mind busy by learning about ASD. This is why I decided to complete my master's degree and Ph.D. in special education and write this research study on my son.

# Acceptance

The two other mothers and I reported that we found it difficult to accept reality when our children were first diagnosed with ASD, even though our children needed our help at this stage. We were shocked and began to blame ourselves, but gradually, we became more accepting and positive. Patience and tolerance significantly contributed to the acceptance process, and we provided what we could to meet our children's needs and help them become independent. Amal described this.

I sent my daughter to paid private centers and provided her with a special education specialist who works with her for an hour a day. The specialist teaches her daily life skills. I want my daughter to rely on herself for her personal hygiene. The specialist also prepares her for puberty and teaches her, using dolls, how to keep herself clean during her period. (Amal)

#### DISCUSSION

This study explored my personal and other mothers' experiences by identifying the most common parenting challenges facing mothers of children with ASD in Saudi Arabia and exploring strategies to help mothers face these challenges. This study concluded that mothers of children with ASD in Saudi Arabia face many parental challenges, foremost of which is the mothers' ignorance of ASD, their rights, and the rights of their children. Other challenges include mothers' feelings of guilt, fear, anxiety, and diminished social relationships, as well as limited availability of educational and diagnostic services.

Mothers in Saudi need more reliable information, awareness, and understanding of ASD. The mothers in this study reported that ignorance of ASD, its causes, and methods of treatment were some of the challenges they faced after their children were diagnosed with ASD. Ignorance of ASD and the ignorance of their rights and the rights of their children led them to

believe the widespread myths about ASD (e.g., that an evil spirit and vaccinations cause ASD and can be treated with the Qur'an). The mothers' ignorance of ASD lead to their belief that ASD is a disease that can be cured. Thus, they continued to search for a cure, which made them vulnerable to believing myths that could harm their children.

These findings are consistent with Hebert (2014), who explored parents' experiences surrounding intervention decisions. The researchers found that parents of children with ASD who lived in the U.S. are always looking for treatment for their children due to their lack of awareness about the nature of ASD. The parents reported that their ignorance of ASD and belief in false and fixed beliefs about the causes of ASD led to delays in diagnosis and early interventions, which harmed their children's improvement (Hebert, 2014). In this study, the mothers' and my ignorance of ASD and our rights might be related to misinformation online. Although there is information available on the internet in Arabic for parents of children with ASD, it is not from reliable scientific sources (Alqahtani, 2012).

It is common for parents of children with ASD to worry about the future of their children (Ogston et al., 2011). Children with ASD need different levels of support. Some only need a little support and can go to college, get a job, and build a family. On the other hand, some individuals with ASD need a high level of continuous support to perform their daily tasks. Mothers in this study were concerned they might be unable to support their children in the future, perhaps because of old age, illness, or death. This is consistent with a study by Cox et al. (2015) that reported that parents from the U.S. and Canada who have children with ASD reported a higher level of anxiety and stress (e.g., fear of death) compared to parents of children without disabilities.

Diminished social relationships were one of the challenges reported by the mothers in this study. This is also reported in the literature. For example, Hauser-Cram et al. (2001) found that parents from the U.S. reported that behavioral problems of children with developmental delays are among the most pressing issues and challenges facing their parents. Many parents feel isolated because their friends, family, and society do not understand and do not accept their children's behavior. At the same time, mothers (both in my study and a study by Dunn et al. [2001] with parents from the U.S.) cannot leave their children with ASD with other caregivers or maids because they are not trained to deal with the needs of the child.

Mothers in this study reported that one of the challenges they faced in raising a child with ASD in Saudi Arabia was the lack of educational services. This included a lack of qualified teachers in the field of ASD, curricula not modified to suit the abilities of children with ASD, and classrooms in public schools not equipped with the tools and resources needed by children with ASD. Also, children with ASD do not receive behavior modification sessions at school, which forces parents to pay for these sessions at paid ASD centers. In addition, the mothers in this study and I reported a lack of adequate diagnostic services. For example, there were no specialists to conduct the diagnostic process and no clear and specific tools for diagnostic specialists to follow. These findings agree with previous studies exploring parents' experiences in Saudi and their dissatisfaction with the educational and diagnostic services (Alnemary et al., 2017; Hemdi & Daley, 2017; Sahab & Balubaid, 2017).

The lack of educational and diagnostic services in Saudi can be attributed to two factors: (1) the increase in the rates of ASD among children throughout the world, and (2) the enormous financial cost required to establish specialized centers supported by professionals who are familiar with how to support those with ASD and their families (Asi, 2016). The incidence of ASD continues to increase, and services are costly. For example, the United States spends more than \$394 million annually on services for diagnosing and educating children with ASD (Asi, 2016). This monetary cost hinders most developing countries and Saudi Arabia from providing good education and diagnostic services. Another factor making the lack of education and diagnostic services a challenge is that the efforts in Saudi Arabia to develop services provided to people with special needs initially focused on people with intellectual disabilities, hearing impairments, and visual impairments (Aldabas, 2015). There is a lack of similar interest dedicated to children with ASD. For example, there is only limited interest in establishing ASD-specific schools or integrating children with ASD with non-disabled students in public schools. School decisions should be made in ways that best suit their abilities and educational and psychological needs.

Mothers in this study reported that distraction and accepting reality helped them overcome the challenges of raising a child with ASD. The mothers in this study decided to see past the challenges, move forward, educate themselves, assume responsibility, look for alternative rewards, and take good care of their children. This

is consistent with the results of the study by Al-Kandari et al. (2017), who found that parents in Kuwait reported that the only way to face the challenges of ASD is to accept the situation and find ways to deal with it. The parents in the Al-Kandari et al. (2017) study stated that acceptance increased their pain tolerance, and distraction lowered pain intensity. This study's findings also agree with existing literature on parents in the U.S. For example, the findings of Kuhaneck et al. (2010), which explored parents' experiences in the U.S., reported the importance of obtaining knowledge about ASD, and it confirmed that "knowledge is power" (p. 6).

# Implications for Research, Practice, and Policy in Saudi Arabia

This study could impact national policy and practice in Saudi Arabia. For example, mothers in this study stated that diagnosis was a challenge. Therefore, the Education and Health Ministries in Saudi Arabia could work together to standardize diagnostic tools and establish early identification processes for children with ASD. For example, the Diagnostic and Statistical Manual of Mental Disorders (DSM-5, American Psychiatric Association, 2022) is the standard tool for diagnosing ASD and other disorders in the U.S. Trained specialists use it to standardize diagnosis.

In this study, mothers reported difficulties accessing information and knowledge that would have helped them better understand the needs of children with ASD because most information was available only in English or other non-Arabic languages. Furthermore, the information provided in Arabic was from unreliable sources. Therefore, ASD associations and universities should translate reliable sources into Arabic and provide this information to parents and community service providers. Although the government provides free public education, services for children with disabilities (and ASD), and a monthly stipend, the public schools are not equipped to support children with ASD and lack qualified teachers. Also, the government stipend does not cover the costs associated with children's needs. Most Saudi families still spend much money on private schools or educating their children in neighboring countries that offer high-quality special education services (Alnemary et al., 2017). Therefore, the Saudi government could increase the monthly stipend for families of children with ASD to pay for services that are not free. This would meet all the requirements and needs of their children. The Saudi government could also build more centers that provide quality services for children

with ASD, and encourage more professionals, male and female, to specialize in ASD care (e.g., psychiatrists, counselors, social workers, teachers, physical therapists, occupational therapists, speech therapists). ASD specialists in Saudi Arabia also need continuous training. For example, in the U.S., the government has provided funding to allow special education professionals to obtain free materials and online modules (e.g., Autism Focused Intervention Resources & Modules [AFIRM]).

# **Study Limitations**

The two main limitations of this study revolve around the ability to generalize the findings to many diverse individuals. The first main limitation is that interviews were conducted with a small number of participants who are Saudi mothers of children with ASD, and all of them are from WhatsApp groups. Therefore, the results may only represent those who can access the internet and join WhatsApp groups. However, the number of participants is usually small in qualitative studies, especially in autoethnography research, because the main goal is to obtain more in-depth insights supporting the researcher's autoethnographic writing (Wall, 2008). The second main limitation of this study was that only mothers of children with ASD were interviewed but not fathers nor any other members of the family, which in Saudi Arabia often includes grandparents, uncles, aunts, and siblings. Interviews with other family members who interact with the child directly could have provided differing perspectives. Despite these limitations, the researcher's dual role as a participant and researcher may produce valuable data that helps explore the experiences and overcome the challenges facing families of children with ASD in Saudi Arabia.

#### CONCLUSIONS

This study confirms what other studies have reported: Saudi mothers of children with ASD faced many challenges that, in turn, increased their stress and fear. Mothers reported that their challenges are stressful and would like coping strategies to overcome them (consistent with Khan et al., 2020). These challenges affect many areas of their psychological and economic health, as well as their social lives. Therefore, future research should continue to search for strategies to address the challenges of mothers and families of children with ASD in Saudi Arabia. These strategies could have a significant impact on the quality of life of the parents as well as the child (Al-Kandari et al., 2017).

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# An International Investigation of Psychological Distress among Special Education Majors During the COVID-19 Pandemic: Egypt, Turkey, and the United States

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#### **Abstract**

University students are among the vulnerable populations severely affected by the COVID-19 pandemic. The present study was designed to investigate the uncertainty experienced by 472 students from universities in Egypt, the United States, and Turkey during the pandemic and to examine the variables predictive of students' psychological distress. A one-way MANOVA was performed to test the differences in uncertainty among students, and a hierarchical multiple regression was conducted to determine variables predictive of psychological distress. The results showed that American students scored significantly lower than Turkish and Egyptian students in emotional uncertainty, but there were no statistical differences between Turkish and Egyptian students. Turkish students' scores were significantly lower than Egyptian and American students regarding their desire for change, but Egyptian and American students showed no significant difference. Cognitive uncertainty or the desire to be prepared for emergencies such as the COVID-19 pandemic significantly impacted students' overall response. The variables most highly predictive of psychological distress were job loss, emotional uncertainty, and financial stress. Higher education institutions worldwide may benefit from these findings when developing policies and systems to support students during this and future pandemics.

Keywords: university students, uncertainty, psychological distress, financial stress, COVID-19

#### INTRODUCTION

In March 2020, the World Health Organization declared COVID-19 a global pandemic (World Health Organization 2021). Governments worldwide issued restrictions, including lockdowns, social distancing, and voluntary self-isolation (Brooks et al., 2020; Sharma et al., 2020) to control the spread of COVID-19. In Egypt, the government closed non-essential businesses, restricted gatherings, and constrained mobility. In addition, schools and universities were closed, and classes were held online (Biltagy, 2021; Ghazawy et al., 2020). The Turkish government took similar measures to stop the spread of the coronavirus, and citizens were asked to quarantine at home voluntarily to reduce the spread of infection (Satici et al., 2023). Although the U.S. did not have a unified national strategy, most states adopted stay-at-home orders (Dave et al., 2020), and higher education institutions across the country switched to online learning to prevent widespread transmission of the COVID-19 virus (Gewin, 2020).

The restrictions issued by governments to control the outbreak of COVID-19 have affected university students physically, academically, financially, and psychologically. University students' lives dramatically changed as they were asked to be confined to their homes, social interactions were restricted, and they had to adapt to online learning platforms. The switch to online learning resulted in phenomenal difficulties for students (Kecojevic et al., 2020). Many experienced a lack of necessary resources, including communication devices and uninterrupted high-speed internet connections required with online education (Sahu, 2020). Others had difficulties with courses not initially designed for online delivery (Lassoued et al., 2020), which likely demotivated students to continue online classes regularly (Zaman, 2020). Additional challenges included concerns about students' health and the health of family members during the pandemic (Cao et al., 2020; Odriozola-González et al., 2020). Financial uncertainties, especially among students who worked in service industries, were severely impacted by prolonged closures (Kecojevic et al., 2020).

The disruptions caused by COVID-19 affected many university students' academic and social lives and their personal finances, all of which could undoubtedly result in psychological distress among this population (Cao et al., 2020). Psychological distress can significantly impair students' physical health, educational success, social interactions, and future employment opportunities (Kecojevic et al., 2020). As such, it is essential to understand the impact COVID-19 had on university

students by examining the risk factors associated with students' psychological distress secondary to the pandemic. Because the pandemic is a worldwide phenomenon, examining whether the psychological risk factors are consistent across different countries is also essential, as understanding the factors that contribute to psychological distress among students may help universities provide adequate resources to address the emerging mental health crisis of those students at greatest risk.

# **Psychological Distress**

Before the pandemic, students across the globe were struggling with elevated levels of stress, depression, anxiety, lack of self-esteem, psychosomatic problems, substance abuse, and suicidality (Holm-Hadulla & Koutsoukou-Argyraki, 2015); however, these issues increased considerably after the onset of COVID-19 (Ahmed et al., 2020; Fruehwirth et al., 2021). For example, in a longitudinal study among students attending a public university in the U.S., researchers found anxiety and depressive symptoms were more significant in April 2020 than in prior months (Zimmermann et al., 2020). In another longitudinal study of first-year university students, researchers discovered the prevalence of moderate-severe anxiety increased from 18.1% before the pandemic to 25.3% within four months after the pandemic began, and the prevalence of moderate-severe depression increased from 21.5% to 31.7% (Fruehwirth et al., 2021). Cross-sectional studies regarding the impact of COVID-19 on university students have also been showing heightened mental health problems, including depression, anxiety, stress, fear, substance abuse, poor sleep quality as well as suicidal behavior (Cao et al., 2020; Kaparounaki et al., 2020). In Egypt, 70.5% of undergraduate students reported symptoms of depression, 53.6% had anxiety, and 47.8% reported feeling stressed due to COVID-19 (Ghazawy et al., 2020). A study of the pandemic's psychological effects on Turkish university students showed that 64.6% reported symptoms of depression, 48.6% reported symptoms of anxiety, 45.2% reported feeling stressed, and 34.5% of the participants reported having symptoms of post-traumatic stress disorder (Cam et al., 2022).

The most frequently reported factors associated with psychological distress among university students are those related to changes in academic work and social life. Researchers have found depression and anxiety rates were higher for those who had trouble switching to online lectures, changes in communication means with instructors, new assessment methods, and different workloads (Cao et al., 2020; Fruehwirth et al., 2021).

Disturbances in social life have also been reported as risk factors for psychological distress among university students. These factors include closed dorms and having to move back home, being distant from friends, colleagues, or relatives, and being unable to attend parties and travel (Ma & Miller, 2021; Villani et al., 2020). Another factor associated with anxiety and depression among students was a COVID-19 diagnosis among family or friends (Browning et al. 2021).

Although researchers have identified many risk factors for psychological distress among university students after COVID-19, less is known about the effect on students' financial situation and uncertainties about their future academic and employment opportunities. The information we do have indicates job loss, worries about their financial situation, and uncertainties about future education and careers are among the most significant risk factors for depression and anxiety among university students (Brooks et al., 2020; Statista, 2021). To augment the literature regarding psychological distress among university students, it is essential to consider the effects of another set of determinants, namely financial stress and uncertainty. These factors may help inform universities about mental health interventions and additional supports students may need during the COVID-19 pandemic and similar situations.

### **Financial Stress**

Robb (2017) defined financial stress as difficulty meeting financial obligations. Several studies have shown university students across the globe experience heightened levels of financial stress due to COVID-19 (Ela et al., 2021; Zimmermann et al., 2021). According to a survey by the National College Student, 30% of U.S. students reported losing a job needed to pay for their tuition, 77% reported the pandemic reduced their ability to earn income to support their education, and 64% stated their need for financial aid increased due to the pandemic (Scholarship American, 2020). The pandemic has had a tremendous impact on the economic situation of university students, as many students faced job losses or reduced working hours (Aristovnik et al., 2020). In a study regarding the pandemic-related concerns of university students across seven countries, many students reported they worked to pay for college, making it difficult for them to maintain or seek employment (Hawley et al., 2021).

Researchers have documented the association between financial stress and psychological distress (Lee et al., 2015; Linander et al., 2015). Notably, individuals who struggle with financial stressors due to the loss of

employment and increased debts are prone to anxiety and depression (Blustein et al., 2019). The COVID-19 pandemic has threatened peoples' financial status because of disruptions to business operations and global supply chains, and young adults who have financial difficulties caused by the pandemic are experiencing high levels of psychological distress (Varma et al., 2021). To our knowledge, the relationship between financial stress and psychological distress among university students has not been investigated in the wake of the pandemic. However, based on available evidence, the pandemic has exacerbated the financial strain among many university students, and this pressure is likely to increase psychological distress among a population that is already at risk for mental health problems.

# Uncertainty

The lack of knowledge regarding COVID-19 has caused a state of uncertainty. People are still determining the reason for the development of COVID-19 and the symptoms of the virus, the duration of containment secondary to the virus, and the personal, economic, and societal factors impacted by COVID-19. Research indicates university students are consumed by uncertainties about their academic work and future careers (Hawley et al., 2021; Nishimura et al., 2021). In a study among 30,383 university students across 62 countries, students indicated the switch to online education and online examinations increased their level of uncertainty because they involved new teaching and assessment strategies (Aristovnik et al., 2020). In another study, university students from several countries reported feeling uncertain about whether they could find employment in their selected field and worry about finding a job after graduation (Hawley et al., 2021).

Uncertainty regarding the future is a risk factor for psychological distress. For years, we have known individuals who have high levels of uncertainty are at risk for anxiety and depression (Freeston et al., 1994). Among university students, uncertainty of the consequences of COVID-19 has produced significant impacts on their mental health. For example, the uncertainty and drastic change caused by COVID-19 triggered substantial psychological distress among medical students in Japan (Nishimura et al., 2021). University students from Bangladesh reported stress due to uncertainty over their academic and career plans (Ela et al., 2021). A review of the psychological impacts of COVID-19 among university students also showed many felt increased levels of stress, anxiety, and depression due to the uncertainty of their university education and future

employment (Sankhi & Marasine, 2020). The available studies, albeit limited, indicate university students may experience psychological distress due to the uncertainty caused by COVID-19.

# Gender Differences in the Impacts of the COVID-19 Pandemic

Several studies conducted with college student populations identified female students as being more vulnerable than male students to psychological distress during the COVID-19 pandemic (Aristovnik et al., 2020; Sundarasen et al., 2020; Wang & Zhao, 2020). A study of the psychological impacts of COVID-19 among university students in seven U.S. states found that female students were more adversely impacted by the psychological effects of the pandemic (Browning et al., 2021). In addition, a longitudinal study of students at a U.S. public university found that, compared to male students, female students experienced more significant disruptions in their daily activities, mental and physical health, and personal finances (Zimmermann et al., 2021). Furthermore, it was found that female students exhibited higher levels of concern than male students regarding the impacts of the pandemic on their professional careers and ability to pursue their academic goals (Aristovnik et al., 2020). Sundarasen et al. (2020) attributed these gender disparities to increased emotional expression, lower tolerance for uncertainty, and less efficient coping strategies among female students. Uncertainty impacts the financial, mental, psychological, and physiological dimensions of women's lives. Past research has concluded that differences exist in how and what the sexes experience when facing uncertainty. Disparities in health outcomes between men and women widened markedly during the COVID-19 pandemic (Nguyen, 2023).

Furthermore, women were more likely to suffer unemployment as the demand for labor participation shrank due to massive closures and business bankruptcies (Nguyen, 2023). Uncertainty arouses anxiety and fear. In an experimental study using a non-clinical sample of 67 individuals, Burani and Nelson (2020) found that women reported more significant panic symptoms than men when anticipating unpredictable threats.

# Significance of the Study

Human capital is an indispensable asset, and a school needs to enlighten and cultivate young minds. Teachers' myriad roles include facilitating learning, providing guidance, and disseminating knowledge so that students can develop the necessary skill set to function

in contemporary society. Therefore, it is imperative for teachers to not only master effective pedagogical instructions but also maintain good mental health to perform challenging tasks in highly demanding educational settings. This is particularly true of special education teachers, who often work with students requiring individualized assistance and attention. Regardless of culture and country, teaching students with special needs can be a mentally draining and physically taxing profession. Indeed, Zhang et al. (2020) found a strong correlation between psychological resilience and mental distress symptoms in a sample of 681 special education teachers in China.

Research has shown that the COVID-19 pandemic has negatively impacted the mental health of individuals in the teaching profession. In a work burnout study of 468 American special education teachers early in the COVID-19 pandemic, 38.4% of respondents met the clinical criteria for generalized anxiety disorder, a rate 12.4 times higher than the general U.S. population (Cormier et al., 2021). Moreover, 37.6% met the clinical criteria for major depressive disorder, a rate 5.6 times higher than for average Americans (Cormier et al., 2021). Similarly, McGrew, Ruble, Cormier, and Dueber (2023) noted that special education teachers were more mentally worn out than general education teachers. The stress level was even more pronounced among special education teachers working in rural areas, who they felt isolated and felt they were not getting support from parents and administrators (Ruble et al., 2023).

According to Browning et al. (2021), university students are among the vulnerable populations that have been severely affected by the COVID-19 pandemic. Given the importance of understanding the psychological well-being of special education teachers during a global public health crisis, this study aimed to fill the void on this topic in the mental health and special education literature. The purpose of the present study was to examine the psychological distress experienced by university students during the COVID-19 pandemic across three nations. Specifically, we investigated responses to uncertainty among university students from different countries to ascertain how they were influenced by the pandemic and how they coped with psychological distress when facing this unprecedented global endemic. Two research questions guided the study (1) Are there differences in the types of response to uncertainty among Egyptian, American, and Turkish students? and (2) What demographic, psychological, cognitive, and financial variables were predictive of psychological distress during the pandemic?

#### **METHODS**

# **Participants**

A total of 475 university students were recruited from three universities: one in Egypt, a university in the United States and a university located in Turkey. The chi-square significance test of Mahalanobis distances detected three multivariate outliers, which were removed from the data set resulting a final sample of 472. Table 1 displays the demographic characteristics of the participants. The sample consisted of 150 (31.8%) Egyptians, 208 (44.1%) Turks, and 114 (24.2%) Americans. The ages of the student participants ranged between 17 and 45 years with a mean of  $22.19 (\pm 3.63)$ . Most of the students were single (n = 418, 88.6%), female (n = 341, 72.2%), and unemployed (n = 325,68.9%). In terms of class standing, seniors made up the largest group (n = 154, 32.6%), followed by freshmen (n = 144, 30.5%). While 251 (53.2%) students reported experiencing a decrease in income due to the pandemic economic lockdowns, 221 (46.8%) were not affected.

#### Measures

### **Uncertainty Response Scale**

The Uncertainty Response Scale (URS; Greco & Roger, 2001) is designed to measure types of response to uncertainty. The scale consists of 48 items with a 4-point Likert scale ranging from 1 = never to 4 =always. The instrument has three subscales (1) Emotional Uncertainty, (2) Desire for Change, (3) Cognitive Uncertainty. Items on the scale include, "I get worried when things are changing" and "Uncertainty frightens me." Test-retest reliability of the scale (varies between .79 and .86) and Cronbach's alpha internal consistency of the URS (varies between .85 and .90) demonstrated strong evidence for reliability (Greco & Roger, 2001). For the current study, the Cronbach's alpha reliabilities were .90 for the overall scale, .93 for the Emotional Uncertainty subscale (15 items), .90 for the Desire for Change subscale (16 items), and .90 for the Cognitive Uncertainty subscale (17 items).

# Depression, Anxiety, and Stress Scales

The *Depression*, *Anxiety*, *and Stress Scales* (DASS-21; Norton, 2007) is a construct designed to measure psychological distress. This instrument consists of 21 items with a 4-point Likert scale ranging from 0 = Did not apply to me at all to 3 = Applied to me very much, or most of the time. The DASS-21 includes statements about how a person has felt in the past week and includes items such as, "I found it hard to wind down,"

Table 1 Demographic Characteristics of Participants (n = 472).

			Egypt	Turkey	USA
Age		mean±(sd)	21 (±2)	22 (±4)	23 (±4)
Sex	Female	N	130	140	71
		%	86.7	67.3	62.3
	Male	N	20	68	43
		%	13.3	32.7	37.7
Marital status	Single	N	142	189	87
		%	94.7	90.9	76.3
	Married	N	8	19	21
		%	5.3	9.1	18.4
	Divorced	N	0	0	6
		%	0.0	0.0	5.3
Class standing	Freshman	N	15	26	14
		%	10.0	12.5	12.3
	Sophomore	N	23	98	23
		%	15.3	47.1	20.2
	Junior	N	52	34	33
		%	34.7	16.3	28.9
	Senior	N	60	50	44
		%	40.0	24.0	38.6
Employment	Full-time	N	4	21	35
status		%	2.7	10.1	30.7
	Part-time	N	32	9	38
		%	21.3	4.3	33.3
	Furloughed /	N	4	2	2
	Leave of absence	%	2.7	1.0	1.8
	Unemployed	N	110	176	39
		%	73.3	84.6	34.2
Decrease in per-	No	N	60	103	58
sonal income		%	40.0	49.5	50.9
	Yes	N	90	105	56
		%	60.0	50.5	49.1
Change in family	No	N	51	60	41
members' em-		%	34.0	28.8	36.0
ployment status	Yes	N	99	148	73
		%	66.0	71.2	64.0

and I felt that life was meaningless." Internal consistency reliability of the DASS-21 ranges from .78 to .87, indicating the scale is a reliable instrument (Norton, 2007). For the current study, Cronbach's alpha reliability for the DASS-21 was .95.

# Financial Stress Scale-College Version

The Financial Stress Scale College Version (FSS-CV; Northern, O'Brien, & Goetz, 2010) measures the financial stress level of undergraduate students. This instrument consists of 13 items with a 4-point Likert scale ranging from 1 = never to 4 = all of the time. Students are asked to rate how often they have thought about

financial events over the past six months and items include, "Being in a job where your work isn't steady/ predictable" and "Barely making enough money to cover expenses." The reliability of the scale was evaluated as .87, showing high internal consistency (Northern, O'Brien, & Goetz, 2010). For the present study, Cronbach's alpha reliability was .82.

# Demographic Questionnaire

This brief survey queried student participants via self-report. Items addressed their age, sex, college major, class standing, marital status, employment status, and whether they experienced a decrease in their income and/or job loss in the family during the COVID-19 pandemic.

#### **Procedure**

Ethical research protocol was reviewed and approved by the host institutional review boards. Permission was obtained from individual professors to recruit their students for the study. A web-based survey was used to collect data in the United States and Turkey while a conventional paper-and-pencil survey was used in Egypt. Participation in the research project was voluntary and no incentive was offered. The amount of time estimated to complete the questionnaire was between 10 and 15 minutes.

#### **Data Analysis**

For the first research question, a one-way MANO-VA analysis was performed to test the differences in the types of response to uncertainty among Egyptian, American, and Turkish students. We checked the assumptions for MANOVA analysis and found no violation of normality across nations for each dependent variable, according to skewness and kurtosis values (ranges between -1 and +1) and normal Q-Q plots. Scatterplots showed a low level of linear relationship between dependent variables for each country. There was no singularity or multicollinearity problem based on pairwise correlations, tolerance, condition index, and VIF values (below 10). However, Box's M test of equality of covariance matrices showed significant deviation (p < .05). Except for emotional uncertainty, there was no violation of homogeneity of variances, according to Levene's test (p > .05). We then performed the one-way MANOVA for the independent variable nation (3 levels) and the dependent variables emotional uncertainty, desire for change, and cognitive uncertainty. Dunnett C test for multiple comparisons were performed because homogeneity of variance assumption was not satisfied for at least one group. Bonferroni

adjustments were made for multiple comparisons.

For the second research question, a hierarchical multiple regression consisting of two blocks was performed to determine demographic, psychological, cognitive, and financial variables that are predictive of psychological distress during the pandemic. We checked the assumptions for this regression analysis method and concluded there were low levels of linear relationships between the independent and dependent variables according to scatterplots. Pairwise correlations, tolerance, condition index, and VIF values (below 10) showed there was no singularity or multicollinearity problem. The residuals (errors) were approximately normally distributed according to a normal P-P plot of the regression standardized residuals. The scatterplot of the residuals data did not show the characteristics of a homoscedastic distribution. After ensuring that there were no significant deviations in the assumptions, a hierarchical multiple regression with two block was performed. The dependent variable of the analysis was psychological distress scale scores. In the first block, the independent variables were financial stress, emotional uncertainty, desire for change, and cognitive uncertainty. Nation, sex, employment status, decrease in income, and job loss were the independent variables in the second block. Since all variables in the second block were categorical, they were dummy coded prior to entering the regression equation. All analyzes were performed using IBM SPSS Version 26 Software.

#### RESULTS

# RO1

One-way MANOVA analysis results revealed there was a statistically significant difference in the types of response to uncertainty among Egyptian, American, and Turkish students, F(6, 934) = 23.918, p < .0005; Wilk's  $\Lambda = 0.751$ , partial  $\eta^2 = .133$ . Tests of between-subjects effects showed nation had a statistically significant effect on emotional uncertainty (F[2, 469] = 47.443; p< .0005; partial  $\eta^2 = .168$ ), desire for change (F[2, 469]= 22.330; p < .0005; partial  $\eta^2 = .087$ ) and cognitive uncertainty scores (F[2, 469] = 9.109; p < .0005; partial $\eta^2 = .037$ ). Since homogeneity of variance assumption was not satisfied, the Dunnett C post hoc test was performed to make multiple comparisons. The results of the Dunnett C test revealed emotional uncertainty mean scores of American students (M = 26.272, SD =7.354) were statistically significantly (p < .05) lower than scores of Egyptian (M = 36.120, SD = 10.636) and Turkish students (M = 35.236, SD = 8.400). However,

Table 2
Descriptive Statistics and Correlations of Continuous Variables.

							Correlations				
Variable	R	M	SD	S	K	α	1	2	3	4	5
1. Emotional uncertainty	15-60	33.35	9.79	.49	.11	.93	_				
2. Desire for change	16-64	42.95	9.09	.18	07	.89	16**	_			
3. Cognitive uncertainty	23-68	50.57	9.36	11	53	.90	.20**	.27**	_		
4. Financial stress	7-28	14.13	4.81	.83	.36	.82	.37**	.00	.11*	_	
5. Psychological distress	0-63	20.91	14.59	.63	25	.95	.63**	07	.10*	.44**	_

Note. n = 472. R = Range; M = Mean; SD = Standard Deviation; S = Skewness; K = Kurtosis;  $\alpha$  = Cronbach's alpha  $p \le .05, p \le .01$ 

emotional uncertainty mean scores of Egyptian and Turkish students were not statistically significantly different (p < .05).

Desire for change mean scores of Turkish students (M = 39.947, SD = 8.292) were statistically significantly (p < .05) lower than scores of Egyptian (M = 45.567, SD = 8.822) and American students (M = 45.000, SD = 9.257). However, desire for change mean scores of Egyptian and American students were not statistically significantly different (p < .05). Cognitive uncertainty mean scores of American students (M = 50.535, SD = 10.275) were not statistically significantly (p < .05) different from scores of Egyptian (M = 53.020, SD = 9.030) and Turkish students (M = 48.813, SD = 8.693). However, cognitive uncertainty mean scores of Turkish students were statistically significantly (p < .05) lower than scores of Egyptian students.

#### RO<sub>2</sub>

Prior to performing hierarchical multiple regression analyses, we evaluated the descriptive statistics and correlations regarding dependent and independent variables. The frequency statistics of categorical variables were given in participants section. Descriptive statistics and correlations of continuous variables are reported in Table 2. The correlations among the study variables ranged from small to large. Psychological distress and emotional uncertainty had the strongest correlation (r = .63, p < .01), followed by psychological distress and financial stress (r = .44, p < .01), emotional uncertainty and financial stress (r = .37, p < .01), cognitive uncertainty and desire for change (r = .27, p < .01), cognitive uncertainty and emotional uncertainty (r = .20, p < .01), financial stress and cognitive uncertainty (r = .11, p)

< .05), and psychological distress and cognitive uncertainty (r = .10, p < .05). Emotional uncertainty and desire for change was negatively correlated (r = -.16, p < .01).

Results from hierarchical multiple regression analyses predicting psychological distress are presented in Table 3. An  $R^2$  value of .44 showed the independent variables in the first model explained 44% of the variability of dependent variable psychological distress. For the second model, all independent variables explained 47% of the variability of this variable. Independent variables added in the second model increase  $R^2$  value .03 points which leaded to a significant change in F value (p < .05). The results also revealed the independent variables statistically significantly predicted the dependent variable, for the first model F(4, 467) = 93.237, p < .001 and the second model F(12, 459) = 33.197, p < .001 (i.e., the regression model is a good fit of the data).

The variables that statistically significantly predicted psychological distress were emotional uncertainty  $t(466) = 14.35, \beta = .56, p < .001$  and financial stress  $t(466) = 6.22, \beta = .23, p < .001$  for the first model. Thus, a 1-point increase in emotional uncertainty and financial stress scores yielded an approximately half and a quarter standard deviation increase in psychological distress scores when controlling for other variables, respectively. For the second model, emotional uncertainty  $t(458) = 12.84, \beta = .54, p < .001$ , financial stress t(458)= 5.60,  $\beta$  = .22, p < .001, nationality (being Turkish)  $t(458) = -2.63, \beta = -.16, p < .01$ , and job loss during the pandemic  $t(458) = 2.14, \beta = .08, p < .05$  were the significant predictors. Thus, a 1-point increase in emotional uncertainty, financial stress, and job loss during the pandemic yielded an approximately half, a quarter, and

Table 3
Hierarchical Multiple Regression Analysis Predicting Psychological Distress (n = 472).

						95% Confidence Interval for <i>B</i>		
Model	Variables	F	∆R2	В	SE	β	Lower Bound	Upper Bound
1	(Constant)			-15.18**	3.70		-22.45	-7.92
	Emotional uncertainty			0.83**	0.06	0.56	0.72	0.94
	Desire for change	93.24**	0.44	0.06	0.06	0.03	-0.06	0.17
	Cognitive uncertainty			-0.08	0.06	-0.05	-0.19	0.04
	Financial stress			0.70**	0.11	0.23	0.48	0.93
2	(Constant)			-9.60*	4.51		-18.46	-0.75
	Emotional uncertainty			0.80*	0.06	0.54	0.68	0.92
	Desire for change			0.02	0.06	0.01	-0.10	0.13
	Cognitive uncertainty			-0.10	0.06	-0.06	-0.21	0.01
	Financial stress			0.68**	0.12	0.22	0.44	0.91
	Nation (Turkey)			-3.36**	1.28	-0.11	-5.88	-0.85
	Nation (USA)	33.20**	0.47	-1.53	1.56	-0.04	-4.60	1.54
	Gender (Male)			-1.88	1.23	-0.06	-4.30	0.53
	Employment (Part-time)			-2.70	1.93	-0.07	-6.50	1.10
	Employment (Furloughed/ Leave of absence)			1.67	4.19	0.01	-6.57	9.91
	Employment (Unemployed)			-0.31	1.70	-0.01	-3.66	3.04
	Decrease in income			-0.15	1.15	-0.01	-2.41	2.10
	Job loss			2.53*	1.18	0.08	0.21	4.85
Note: *	$p \le .05, **p \le .01$							

.08 standard deviation increase in psychological distress scores, respectively. However, having a 1-point increase in nationality of being Turkish yielded .16 standard deviation decrease in psychological distress scores.

#### DISCUSSION

# **Compliance with Public Health Decrees**

The interpretation of the study's results must be understood in the public health policy context in which each participating institution operated. The pandemic's impacts on the participants' employment status, psychological well-being, financial concerns, learning outcomes, and feelings of uncertainty were both universal and local. In the following paragraphs, we describe how the participating universities in Egypt, Turkey, and the United States, following their respective government guidelines, responded and adapted to the academic emergency caused by the COVID-19 pandemic.

Turkey's first COVID-19 case was detected on March 11, 2020. The next day, the Higher Education Council instructed all universities to temporarily suspend their classes and activities for one week. On March 23, 2020, to prevent the further spread of the disease and to minimize disruptions to education during the crisis, the government enacted a uniform national regulation obliging institutions of higher education to conduct remote teaching and training (Council of Higher Education, 2020). As was the case with other institutions of higher education elsewhere in Turkey, from that date onward for one full year, all lectures and examinations at the second author's university were carried out in the form of digital distance education.

Egypt was ravaged by the coronavirus (Medhat & El Kassas, 2020), and it was the first African nation to report COVID-19 infection (Saied et al., 2021). The Ministry of Health reported the country's first case

on February 14, 2020 (United Nations, 2020). It also became the first nation in the African continent to be infected by COVID-19 (Saied et al., 2021). On March 21, 2020, the Egyptian government closed all places of public gathering including mosques, tourist resorts, schools, and universities (Saied et al., 2021). To ensure student health and to prevent the spread of the virus, the third author's university transitioned to online teaching for the remainder of the school year, residence halls were closed, and student support services migrated online. As universities in Egypt prepared to open the new school year on October 17, 2020, the Ministry of Education implemented several health measures to keep campuses safe (Kandil, 2020). Among these were checking students' body temperature, maintaining small classes, and conducting virtual rather than in-person meetings.

On January 19, 2020, the first known patient with COVID-19 entered the United States (Holshue et al., 2020). The airborne contagion quickly spread from the origin point of entry in Seattle, Washington to the rest of the nation. During the early breakout of the COVID-19 pandemic, the Centers for Diseases Control and Prevention scrambled to explain the nature of the disease to the public and often issued ambiguous if not conflicting recommendations and measures. As a result, the methods by which the 50 state governors handled the public health crisis were divided along the line of partisan ideologue (Gollwitzer et al., 2020). Differing policies led to different outcomes as evidenced by a 2020 New York Times study which indicates that the coronavirus was deadliest where Democrats lived (Medina & Gebeloff, 2020).

Located in a southwestern U.S. state governed by Republicans, the first author's university complied with the decrees issued by the executive branch of the state. On March 21, 2020, the county where the institution is situated had its first confirmed case of COVID-19 (Hildago County, Texas, 2020). The Democrat-controlled city council also imposed a one-week lockdown of the entire city vicinity, including the campus. By late March 2020, all classes had shifted to asynchronous or synchronous teaching, and research with human subjects had been suspended. In the spring semester of 2021, at the behest of the Republican governor, the campus reopened with strict rules, such as safe physical distancing, compulsory mask-wearing, mandatory public health leave when infected, and disinfection of classrooms and laboratories.

COVID-19 was declared a global pandemic in 2020, and mental health problems among students in universities across the world increased exponentially during this pandemic. Some of the primary reasons for this increased psychological distress were academic changes, such as having to take courses online (Fruehwirth, 2021), and life changes that included having to move back home and inability to socialize with friends (Gad et al., 2023; Ma & Miller, 2021). Financial strain also significantly stresses students (Scholarship America, 2020). Indeed, the uncertainty college students worldwide experienced during the pandemic exacerbated their day-to-day concerns, and it is well documented that individuals experiencing uncertainty are at increased risk for developing psychological distress (Reizer et al., 2021). The present study was designed to examine the uncertainty experienced during the pandemic among Egyptian, American, and Turkish students and to ascertain the variables predictive of these students' psychological distress.

Regarding uncertainty, the results showed that American students scored significantly lower than Turkish and Egyptian students on emotional uncertainty; however, there was no statistical difference in emotional uncertainty among Turkish and Egyptian students. This means American students reported feeling less anxious, less depressed, and less frightened than Turkish and Egyptian students when things were changing during the pandemic. One reason for this difference may be that Egypt and Turkey are collectivistic nations compared to Americans, who tend to hold individualistic worldviews. As such, students from Egypt and Turkey may have been concerned about their families, friends, and fellow citizens' well-being instead of worrying primarily about themselves. This may have caused more stress than for American students. In addition, the healthcare system in America is more advanced than in Turkey and Egypt, and knowing they would have access to highly skilled medical teams may have helped to assuage American students' emotional distress.

As for their desire for change or getting excited about new experiences, Turkish students' scores were statistically significantly lower than those of Egyptian and American students. However, Egyptian and American students' desire for change scores were not statistically significantly different. Turkish students were less likely to find the prospect of change during the pandemic exciting or suspenseful than American and Egyptian students. Turkish students also scored significantly lower than Egyptian students on cognitive uncertainty (e.g., less desire for things to be mapped out). However, they

did not differ from American students on the cognitive uncertainty scale. That Turkish students did not experience a suspense-filled reaction to the pandemic suggests they may have been less affected by their inability to control the ambiguities associated with the pandemic. One reason for this may be that most Turkish students were sophomores.

In contrast, most American and Egyptian students were seniors. Turkish students may have been less affected because they were two years away from graduation compared to American and Egyptian students, who may have been concerned about impending future employment. As for American students, needing to have things orderly and mapped out may have been less of an issue because, as noted above, they were less emotionally affected by the pandemic.

Regarding the five study variables assessed (i.e., emotional uncertainty, desire for change, cognitive uncertainty, financial stress, and psychological distress), cognitive uncertainty or the desire to be prepared for emergencies such as the COVID-19 pandemic significantly impacted students' overall response. Commensurate with previous research (e.g., Fruehwirth et al., 2021; Kecojevic et al., 2020), it seems likely this uncertainty was associated with students' having to transition to fully online classes to prevent widespread transmission of COVID-19. Indeed, the most frequently reported factors of psychological distress among university students include those related to changes in their academic work. The highest positive correlation noted in this study was between psychological distress and emotional uncertainty, which would be expected since both the emotional uncertainty scale and the psychological distress scale measure anxiety and depression. These findings are consistent with previous research that showed anxiety and depression were higher for students who had difficulty switching to online lectures and changes in their communications with instructors during the pandemic, as well as those who had to get used to new assessment methods and workload changes (Chirikov et al., 2020; Fruehwirth et al., 2021). Financial stress was also significantly correlated with psychological distress, suggesting that students who experienced financial hardship during the pandemic also experienced more significant levels of psychological distress. Indeed, the COVID-19 pandemic has had a tremendous impact on college students who experienced a job loss or a reduction in work hours (Aristovnik et al., 2020), and the present study provides further evidence of the deleterious influence of financial strain on students' mental health.

The variables most highly predictive of psychological distress among the three groups of students were job loss, emotional uncertainty, and financial stress. Regarding job loss and financial stress, only 24% of Egyptian students, 14% of Turkish students, and 64% of American students had either full or part-time jobs at the time they were surveyed, and roughly half of all students reported they experienced a personal income decrease during the pandemic. The high employment rate among American students is noteworthy as being employed may be why a significantly smaller number of American students reported experiencing emotional uncertainty than Egyptian and Turkish students. In addition, the Egyptian and Turkish students may hold collectivistic worldviews, which would likely entail their desire to help their family members who were experiencing financial hardship during the pandemic, thus escalating both their emotional and psychological distress.

#### Limitations

A few caveats curtail the generalizability of the findings from this study. As with survey research, an inherent shortcoming of the data analysis is its reliance on self-reported responses. Student participants in this study may have underreported the levels of their distress due to shame, guilt, embarrassment, and family pride. In addition, student participants were special education majors, and special education is an occupation that tends to attract females. As such, the present sample had disproportionately few males. It may not provide a complete picture of the types of uncertainty experienced during the pandemic and the variables predictive of students' psychological distress. Furthermore, all three participating institutions were in cities, which may not reflect the parity of resources with their counterparts in less developed regions.

# **Future Research**

This study contributed to the gap in research surrounding psychological distress during a time of uncertainty. It would be helpful to diversify the sample by recruiting student participants from a wide array of majors to reflect the general population better. The impact of the pandemic on the economy also varies between urban and rural settings, where working remotely from home may not be feasible for some. To assess financial stress more accurately, researchers are encouraged to survey students from universities in urban, semi-rural, and rural regions. Future research should also consider incorporating the construct of sex-role expectation to control for the influence of cultural and religious

variables in patriarchal societies. For example, in some Asian and Muslim nations, men are often seen as the primary breadwinners and providers of their families, and this may lead to increased psychological distress. Indeed, one can only imagine the intense pressure they experience when they lose their jobs and cannot provide financial security and satisfy the basic needs of those they love most.

#### **CONCLUSION**

The findings of this study add to the existing literature on the mental health well-being of pre-service special education teachers, who represent the bedrock of inclusive education in elementary and secondary schools. The strength of this international investigation sheds light on how future special education teachers in three different nations dealt with psychological distress during a deadly, unprecedented global pandemic. American students reported struggling more than their counterparts in Egypt and Turkey when facing uncertainty during the pandemic. High psychological distress is noted in all three nations as students transitioned from traditional face-to-face instruction to online and virtual learning. Moreover, American students experienced higher financial stress due to job loss as the economy was shut down unexpectedly. Culturally, American students are expected to work to support their college education, while it is common for Turkish and Egyptian families to help their children with college costs. The knowledge, or lack thereof, about the coronavirus, exacerbated emotional uncertainty among the students. The perceived inability to control the present and future resulted in psychological distress.

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# Timer Visual Formats and Literacy-Based Behavioral Interventions

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#### **Abstract**

This study expanded the literacy-based behavioral intervention (LBBI) literature by exploring the impact of two self-regulation countdown timers with different visual formats on young children during a home-based self-care routine. Using a multiple probe design, we examined the effectiveness of LBBIs and timers in teaching independent toothbrushing and whether the skills would be maintained and generalized. An alternating treatment design assessed whether one of the timers' visual formats had more significant effects on the toothbrushing routine. Results showed that the children dramatically increased their independence and accuracy after using the LBBI stories and timers. These skills were maintained when instruction ended and generalized to the same routine during a different time of day without parental guidance. Each child showed a preference for one timer over another. This study extends previous research on LBBIs and timer use, demonstrating intervention effectiveness with young children.

# **INTRODUCTION**

Teaching self-care skills during the early years of life provides children with opportunities and instruction to become strategic and motivated learners as they learn to feed themselves, dress, and use the restroom as typical self-regulatory routines (Paris & Paris, 2010). As children learn additional self-care skills, such as oral hygiene, they learn other health routines and gain greater autonomy, drawing the attention of educators and healthcare providers while promoting their overall health (American Dental Association, 2018; British Society of Paediatric Dentistry, n.d.). Oral hygiene for children involves brushing, flossing, using mouthwash, and, starting at four years old, brushing their teeth for at least two minutes twice a day.

Most educators agree that one focus of early education should be to promote social-emotional learning, including increasing attention to routines and tasks; typically, this occurs by building different forms of self-regulation into children's instructional methods (Russell et al., 2016). When learning self-care skills, young children also learn to self-regulate. Self-regulation involves skills and actions learned through experiences, instruction, and practice, and these actions can be specifically linked to children's attainment of goals (Paris & Paris, 2010). When children do not learn skills at similar rates as their peers, adults often look for positive behavioral interventions that teach self-regulation in addition to the desired skill(s) (McDougall, 1998; Russell et al., 2016).

Literacy-based behavioral interventions (LBBIs) are grounded in behaviorism (Cooper et al., 2019) and incorporate self-regulation into teaching routines. LBBIs use printed words and visuals to teach new skills and to link skill chains together to perform routines (Bucholz & Brady, 2008). LBBIs were developed to deliver effective instruction in a naturalistic manner, such as reading a story in which the learner is the main character. Unlike story-based interventions that specifically avoid teaching procedures (see Kokina & Kern, 2010; Leaf et al., 2020), LBBIs include structured teaching procedures drawn from behavioral skills training and other forms of learning theory (e.g., discrimination training, modeling, rehearsal), specifically literacy-enabled rehearsal and role-play (Lillard et al., 2013). These interventions have been particularly effective in increasing self-regulation in young children (Cavanaugh et al., 2016).

LBBIs have shown their effectiveness in teaching children and adults, with and without disabilities, across various routines. Initially, LBBIs were delivered by teachers or interventionists in a 1-to-1 format. Current delivery formats include peers, job coaches, and groups. LBBI investigations follow a learning paradigm that teaches new skills, from self-regulation to employment to daily living skills (Brady et al., 2016; Hall Pistorio et al., 2018; Hall Pistorio et al., 2017; Kearney et al., 2018). For example, Brady et al. (2016) investigated teaching self-care skills, including handwashing, to elementary school children with intellectual disabilities using a peer-mediated LBBI storybook. All the children

improved their handwashing, and the behavior was generalized to other environments and maintained after the LBBI was removed.

Two recent investigations demonstrate the potential of LBBI with young children. Hall Pistorio et al. (2017) examined the efficacy of LBBIs in teaching self-regulation skills to two- to four-year-old children. Four children at risk for developmental delays were taught to set timers to increase their engagement in a reading or activity center. In addition, investigators used an electronic LBBI, diverging from traditional paper storybooks based on research that young children may be motivated by electronic delivery modes (Brown, 2015; Kemp et al., 2016). All children made dramatic improvements in engagement. Timer setting is also generalized to new activities or reading centers. Three children were assessed for maintenance, and their skills were maintained after removing the LBBI. A more recent study explored whether LBBIs could be implemented in small groups (Hall Pistorio et al., 2021). Preschool children were given an electronic LBBI during a center activity. All children showed substantial increases in learning kindergarten transition skills, which were generalized to novel materials not included in the teaching activities.

Although these studies consistently demonstrated LBBIs as effective in teaching self-care and other skills in educational and community settings, no research has shown its use with home-based family routines or using parents as facilitators. As early educators and families strive to support young children to meet increasingly rigorous academic standards, it becomes increasingly important for professionals to explore practical, family-friendly behavioral interventions (McGuiggan, 2021). These interventions can support children's progress in reaching developmental milestones related to independent functioning and self-care.

# **Purpose of the Study**

This study aimed to explore further LBBIs as a teaching strategy for young children. Specifically, we extended the LBBI by building a countdown timer into the LBBI story, a behavioral self-control strategy frequently used by teachers to increase children's regulation and engagement (Maag, 1993; McDougall, 1998; Wilkinson, 2008). We also investigated whether the visual format of the timer might differentially affect performance. We sought to discover whether children might respond differently to a more noticeable (larger and poignant visual) countdown display than to a less obvious display (smaller visual that appeared to move slower). We used an electronic storybook as the LBBI medium—a medium only recently investigated for this type of intervention, and only twice with young children (Hall Pistorio et al., 2017; Hall Pistorio et al., 2021)—rather than paper book stories. Specifically, we added self-regulation countdown timers to the intervention to investigate whether they might be effective for younger children who have difficulty completing basic routines or sensory concerns that interfere with some tasks. We posed four research questions:

- 1. Will an LBBI paired with a self-regulation countdown timer increase children's accuracy of a homebased, self-care (toothbrushing) routine?
- 2. If the children increase their accuracy, will these improvements generalize to the same routine conducted during another part of the day, and maintain when the LBBI story is removed?
- 3. If the routine generalizes and maintains, will children show a preference in their selection and use of the timer format when engaging in the routine without parental guidance?

Table 1 *Participant Characteristics*.

Participant	Gender and age	Grade and reading level*	Diagnosis		
William	Male	1st Grade	ASD, Fine motor		
	7	Fountas & Pinnell: Level E	Delay		
Collins	Male	Kindergarten	ADHD, PTSD		
	6	Fountas & Pinnell: Level A			
Lizzy Female		Pre-kindergarten	DD, Speech		
	5	Non-reader; Starting to learn letter sounds	Language delay		
*Fountas & Pinnell (2010) Benchmark Assessment System.					

4. Are there differences in children's performance of the routine based on the visual format of the two self-regulation countdown timers?

### **METHODS**

# **Participants**

Three children between five- and seven-years-old and their mother participated. Children were selected based on their (a) agreement to be observed at home while toothbrushing, (b) interest in using the timers, and (c) parents' request for them to participate in the study. All three were familiar with brushing their teeth and were seen by a dentist every six months. The dentist reported that the children had plaque buildup, and they each needed to improve their toothbrushing skills by brushing all of their teeth for at least two minutes twice daily. Additional participant information can be found in Table 1. The study was reviewed and approved by the authors' university review board.

# **Task and Setting**

The task was selected based on parent information gathered during an interview and children's needs. Parents expressed frustration in keeping the children focused on brushing their teeth across all surfaces for the recommended amount of time. Because the dentist-recommended time was less than five minutes, that time was established as a ceiling, and the task was deemed appropriate for comparing the 5-minute and 60-minute timers.

There were two home settings for all research activities. The intervention (reviewing the LBBI storybook) was implemented by a parent in the training setting (the living room, a few steps from the bathroom) before the *evening* toothbrushing time. This allowed time and space to work through the pages of the LBBI. Then, each child was asked to brush their teeth in the bathroom, which is typically used for this routine, and the child's brushing was observed. Generalization probes (observations without instruction) were taken in the *morning* in the same bathroom. For all sessions, children were observed independent of other family members.

#### **Materials**

During this intervention, two Timers© were compared. A 60-minute and a 5-minute prototype were used (Time Timer, 2019). Both provided a visual countdown

and audible beep when time was complete. Although the timers were identical in size, the countdown window differed so that the 5-minute ceiling in the 5-minute timer took up the entire window, and the 5-minute ceiling in the 60-minute timer was considerably smaller (see Figure 1).

An LBBI toothbrushing story was developed for a PowerPoint presentation based on a task analysis for that skill. The story had 23 slides (pages), each containing one to two sentences and a picture. All sentences were written in Times New Roman, 16-point font. Each image was a 4" x 3" photo depicting a task analysis step taken from a personal point of view. An iPad Power-Point application was used to deliver the LBBI.

# Behavioral Measure, Data Collection, Observer Agreement, and Treatment Fidelity

Children's accuracy of toothbrushing was the behavioral measure. A task analysis was developed that differentiated two sets of skills: (a) actual steps using the toothbrush and (b) steps needed to accomplish the task, but it did not incorporate using the brush inside a child's mouth. The combined task analyses (hereafter, *Total Steps Task Analysis*) contained 36 steps: 19 for brushing and 17 additional steps. The separate task analyses were developed for this routine because each of the three children had mastered some of the extra steps. However, due to sensory or attention issues, they were not appropriately cleaning their teeth to prevent cavities and gum disease, based on their dental evaluations.

Figure 1 LBBI sample page: Timer comparison.

# The timer is set to 5 minutes. I must hurry and complete all steps correctly.



Table 2 Toothbrushing Task Analysis.

# Steps for "Total Steps" Task Analysis

- 1. Pick up toothbrush.
- 2. Pick up toothpaste.
- 3. Open toothpaste tube.
- Put toothpaste on brush. 4.
- 5. Close toothpaste tube.
- 6. Put toothpaste away.
- Turn on water. 7.
- 8. Wet toothbrush.
- 9. Turn off water.
- Brush top left row of teeth. 10.
- 11. Brush bottom left row of teeth.
- 12. Brush top front row of teeth.
- 13. Brush bottom front row of teeth.
- 14. Brush top right row of teeth.
- Brush bottom right row of teeth. 15.
- Brush tongue. 16.
- Spit out water and toothpaste. 17.
- Turn on water. 18.
- 19. Rinse mouth.
- 20. Rinse toothbrush.
- 21. Put toothbrush away.
- 22. Rinse sink.
- 23. Turn off water.
- 24. Dry face and hands.

Steps in bold face do not need to be completed in sequential order. These steps are scored up to three times to accommodate out-of-sequence brushing.

Next, the Total Steps Task Analysis was used to construct the LBBI stories that formed the basis of instruction (see Table 2). Each session was videotaped. Data were collected individually for each child. The primary observer recorded the performance during live observations or by coding the videotapes after the session. Each task analysis step was scored as (a) correct and independent or (b) not attempted or attempted but incorrect. A step was scored as incorrect if the child did not complete it, completed it in error, or omitted a step. Only correct and independent steps were used for instructional decisions; only steps from the task analysis of the actual toothbrushing were included in the graphed results.

Videos were collected by a single observer using an iPad, positioned far enough away from the children so as not to be a distraction, yet close enough to see and hear them (typically, at least five feet behind the child).

The observer stood outside the bathroom door, using the mirror to observe each child. For data collected from the videotapes, the observer watched the video up to two times. Approximately 23% of the videos were emailed to a secondary observer for inter-observer agreement (IOA). Both observers were experienced early childhood and special education teachers enrolled in a graduate program. Both were trained to use the data system on demonstration tapes of various children. Data were collected for IOA purposes during each condition, including 24% of William's, 25% of Collins', and 20% of Lizzy's sessions. Overall agreement across all children was 94% (low of 91% [William] - high of 97% [Lizzy]).

Treatment fidelity was assessed on parent LBBI implementation using a 6-item checklist for each child. The checklist identified whether the parent followed the read, pause, practice, and praise protocol and that the correct timer was available. Fidelity was assessed during the intervention to evaluate how the adult implemented it as intended—an observer collected live data from approximately 10 feet away to collect fidelity data. Fidelity data were collected during 23% of the intervention sessions, yielding 100% fidelity for the three children.

# **Data Analysis**

Data on toothbrushing were analyzed using traditional visual inspection procedures, including central tendency measures during baseline, intervention conditions, and follow-up. Decisions to move from baseline to intervention required the data points to show (a) low accuracy, (b) relative stability, and (c) no evidence of an ascending trend. During the intervention, arranging the 5-minute versus the 60-minute timer was based on a randomization procedure (Kennedy, 2005), specifically a coin flip. Decisions to remove the intervention required each child to have at least five data points with each timer. Because data from the toothbrushing task analysis were used to make decisions, data for the additional steps were summarized, combined with the actual toothbrushing steps, and reported in table format separately (as the Total Steps Task Analysis and as Toothbrushing steps only). Measures of central tendency during all conditions were examined.

The Percent of Non-Overlapping Data (PND) was used post-hoc to estimate the magnitude of effects and to supplement the visual inspection of graphed data for each child (Scruggs & Mastropieri, 2013; Wolery et al., 2014). PND is considered an appropriate method to assess the effects of single-subject designs. PND was

established separately for (a) baseline-to-intervention, (b) baseline-to-follow-up, and (c) between the two intervention conditions. PND also provided an effect size for any generalization effects. For comparisons across conditions, we used Scruggs and Mastropieri's (2013) standards to define effectiveness: (a) an intervention is highly effective if 90–100% of data do not overlap baseline, (b) an intervention is moderately effective if 70–90% of data do not overlap, (c) an intervention is minimally effective if 50–70% of data do not overlap, and (d) an intervention is ineffective if 50% or more of data overlap baseline. To compare the two interventions (5-minute vs 60-minute timer), we applied the PND protocol described by Wolery et al. (2014) for alternating treatment designs; data are assessed in a pair-wise manner so that the first data point for the 5-minute timer is compared to the first data point for the 60-minute timer and so forth until all data pairs in the intervention phase have been compared. This yields the percentage of data in which one intervention is consistently superior to the other.

# **Experimental Procedures**

#### Baseline

During baseline, each child was asked to brush their teeth. No other instruction was given. Both timers were present at the bathroom sink during baseline, although times were not set, and no instruction involving timers or LBBIs was delivered before or during the observation. William had four baseline probes in the evening bathroom training condition; Collins and Lizzy had five in the training condition. All three children had one baseline probe in the generalization condition (morning session).

#### Intervention

The intervention for each child was delivered individually by the child's mother in the living room, a few steps from the bathroom where the children typically brushed their teeth. The mother read the electronic LBBI story to each child following the *read*, *pause*, *practice*, *and praise protocol* used in other LBBI research (Brady et al., 2016; Hall Pistorio et al., 2017). The mother read each page and then paused to give the child a moment to think or respond; if needed, the mother would model the step and ask the child to copy her. If the child completed the step correctly, the mother praised the child and then asked them to swipe the iPad screen to the next page and repeat the protocol. If the child did the step incorrectly, she provided corrective feedback and swiped to the next page. After the mother

and child completed the LBBI, the child was asked to go into the bathroom to brush their teeth. A coin was flipped before the intervention to determine whether the 5-minute- or 60-minute face timer would be used during the routine, and the timer was then set to five minutes. On both timer faces, a green line was at four minutes (i.e., 4 minutes remaining). This green line served as a visual cue for the child to have completed the pre-brushing steps (e.g., putting toothpaste on the toothbrush). There was also a red line at the 1-minute mark on each timer. The red line served as a visual cue for the children to stop brushing and begin the post-brushing steps (e.g., rinsing toothbrush and sink). For William, there were 12 sessions total (six using the 5-minute timer and six using the 60-minute timer). For Collins and Lizzy, there were 10 sessions total (five using the 5-minute timer and five using the 60-minute timer).

### Follow-up and Generalization

Each child had a single generalization (morning session) probe to begin the study and six follow-up probes once the LBBI ended. Three follow-up probes were conducted in the evening (the time previously allocated for intervention), and three were conducted in the morning (the time allocated for generalization sessions). All follow-up probes took place the week after the LBBI procedure, and LBBI materials remained in the family living room. During follow-up observations, both timers were positioned at the bathroom sink, and the children were asked to brush their teeth. The children were informed that they could select and set a timer if preferred; this provided an objective measure of social validity based on child preference (Hanley, 2010).

# **Experimental Design**

To assess whether the LBBI and countdown timers would increase children's toothbrushing (Research Question 1), a multiple probe design across participants was used (Kennedy, 2005). This design required the intervention to be slightly delayed for each child so that experimental effects on the child's behavior could be linked to the onset of intervention. After removing LBBI instruction, a follow-up condition assessed potential maintenance several days later (Research Question 2). Generalization probes during baseline and follow-up observations allowed an assessment of whether the children spontaneously used the timers in the absence of directions to do so (also Research Question 2). We used the follow-up condition to obtain an objective assessment of the social validity of the study (Research Question 3); the follow-up provided the children an

opportunity to act on their perceptions of the acceptability of the timers by selecting their preferences for one or the other timer when they were no longer prompted to do so. Finally, to explore the differential impact of the different timers (whether one of the timer visual formats might have more significant effects on the children's self-care routine [Research Question 4]), we used an alternating treatment design (Kennedy, 2005).

### **Social Validity**

Instead of subjective social validity evaluation based on participants' opinions (rating scales, satisfaction ratings), we used an objective measure—whether children continued to use one of the timers after adults ceased delivering the LBBI and instructions for the timers. Such observational methods are more objective because they do not rely on estimates of participants' intentions (Hanley, 2010; Hurley, 2012). Instead, objective social validity measures assess whether participants demonstrate their intentions to use an intervention by doing so. In this case, we observed whether each child continued to use one of the countdown timers, and if so—which one? This provided information on children's preference to use either the 5-minute or 60-minute timer independent of their success with either and without being requested to use one. During generalization probes, the children were simply asked to brush their teeth, without a timer. Both timers were present for all generalization sessions, and the children could set them if they chose.

#### RESULTS

# Do LBBIs and Timers Improve Children's Performance?

A summary of performance changes for each child across conditions is found in Table 3. Figure 2 demonstrates the effects of the LBBI stories and timers on young children's toothbrushing. William and Collins had relatively stable baselines, with performance low enough to begin intervention following five and six days of baseline. All three participants showed low toothbrushing accuracy (< 30%) during baseline observations, except for Lizzy, who was at 38% during one morning (generalization) baseline session.

Immediately following LBBI implementation and timers, William, Collins, and Lizzy all demonstrated an increase in the accuracy of toothbrushing using both timers; these results are shown in Figure 2. Although William showed a near-steady increase in toothbrushing accuracy, he showed some instability when using the 60-minute timer. However, he ultimately reached 100% accuracy by Day 9 with the 5-minute timer and Day

10 with the 60-minute timer. Collins demonstrated a more dramatic increase in accuracy using both timers, performing consistently at 96% accuracy within four days of beginning the intervention and reaching 100% by the ninth day of intervention using the 5-minute timer. Lizzy showed an ascending trend in her accuracy with both timers and reached 92% by the sixth day of intervention using the 60-minute timer. Unlike William and Collins, Lizzy's typical accuracy was higher using the 60-minute timer than the 5-minute timer.

# **Does Performance Maintain and Generalize?**

Figure 2 also demonstrates the impact of the LBBIs and timers on the maintenance and generalization of the children's toothbrushing. When the LBBI was removed, William, Collins, and Lizzy demonstrated high levels of accuracy and independence (> 84%) during follow-up probes. Because the children decided whether to use a timer during follow-up (and if so, which timer), it is important to examine maintenance effects for each timer type. As depicted in Figure 2, each child most often selected the 60-minute timer during follow-up. William always selected the 60-minute timer, so each of his probes shows that he maintained the skill using that timer. Collins selected the 60-minute timer on 4 of 6 occasions and did not select a preference or set either timer on two occasions. Lizzy used the 60-minute timer on 4 of 6 occasions, the 5-minute timer once, and set both timers on one occasion. During all their follow-up probes, the children showed a high degree of maintenance in performing their self-care routines.

Similar results were found when we examined each child's generalization data (same routine, different time of the day/morning) without parental guidance. All of the children showed high levels of accuracy and independence during generalization using the 60-minute timer. However, William showed a decreasing trend during these morning generalization probes, dropping to 68% after six days. Lizzy was the only child observed during the generalization setting to use the 5-minute timer on one day, and she continued to demonstrate 100% accuracy of performance.

# **PND Estimates**

Using the Scruggs and Mastropieri (2013) standards for PND, there was substantial evidence that the LBBI intervention was highly effective when paired with the timers. PND for all three children between baseline and intervention was 100% for the 5-minute and the 60-minute timers. When comparing baseline to follow-up conditions to assess maintenance, the PND showed the intervention was also highly effective, with

Table 3 *Performance Changes*.

Participant	Baseline	Intervention 5 Minute	Intervention 60 Minute	Follow-up	Generalization	
   William	Total; Teeth	Total; Teeth	Total; Teeth	Total; Teeth	Total; Teeth	
Number of Session	5	6	6	3 with 60 min	3 with 60 min	
Mean	38%; 17%	82%; 74%	69%; 56%	85%; 86%	85%; 86%	
Median	39%; 16%	83%; 71%	65%; 47%	86%; 89%	86%; 89%	
Range	33%-42%; 11%-26%	64%-92%; 37%-100%	53%-86%; 32%-100%	83%-92%; 89%-95%	83%-86%; 68%-100%	
PND	N/A	100%; 100%	100%; 100%	100%; 100%	100%; 100%	
			•			
Collins	Total; Teeth	Total; Teeth	Total; Teeth	Total; Teeth	Total; Teeth	
Number of Session	6	5	5	3 - 1 60 min; 2 none	3 with 60 min	
Mean	53%; 16%	93%; 88%	85%; 77%	93%; 88%	94%; 95%	
Median	50%; 11%	97%; 95%	94%; 95%	92%; 84%	94%; 95%	
Range	50%–58%; 11%–26%	72%–100%; 53%–100%	46%–94%; 37%–95%	92%–94%; 84%–95%	94%; 95%	
PND	N/A	100%; 100%	100%; 100%	100%; 100%	100%; 100%	
Lizzy	Total; Teeth	Total; Teeth	Total; Teeth	Total; Teeth	Total; Teeth	
Number of Session	6	5	5	3 - 2 60 min; 1 both	3 - 2 60 min; 1 - 5 min	
Mean	54%; 16%	81%; 71%	89%; 83%	94%; 93%	98%; 98%	
Median	53%; 16%	81%; 68%	89%; 84%	94%; 95%	97%; 100%	
Range	50%–56%; 11%–16%	69%–92%; 58%–84%	83%–94%; 74%–95%	92%–97%; 89%–95%	97%–100%; 95%–100%	
PND	N/A	100%; 100%	100%; 100%	100%; 100%	100%; 100%	

100% for William's 60-minute timer, 100% for Collins' 60-minute timer, and 100% for Lizzy's 60-minute and 5-minute timers, as well as her simultaneous use of both timers. The generalization effects (from baseline to follow-up) for each child also indicated a highly effective intervention with 100% PND for all three children.

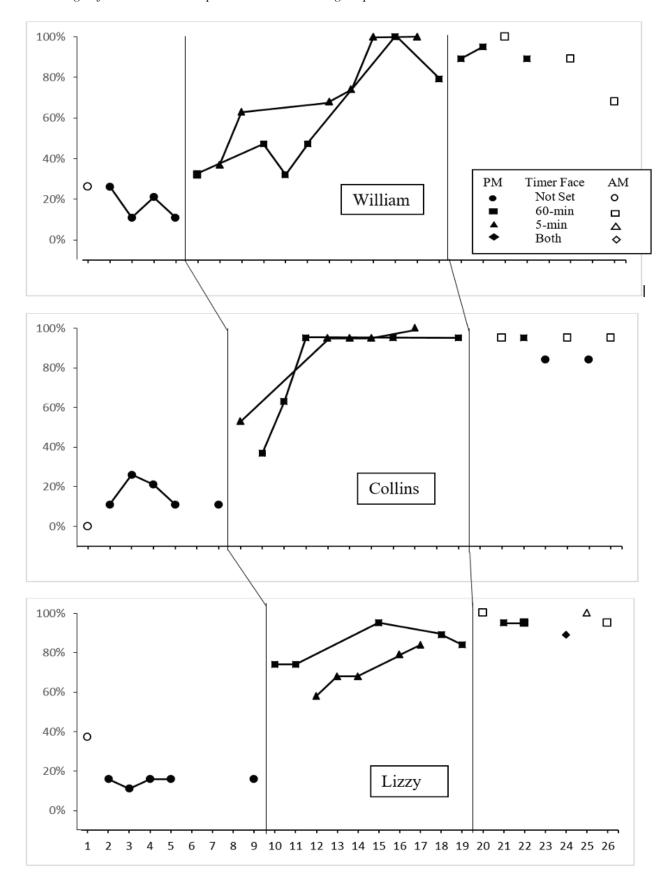
Finally, the Wolery et al. (2014) protocol established whether the children's performance under one of the timers was consistently superior to the other. PND estimates mirror visual inspection findings in Figure 2 but differ somewhat for each child. Over 12 comparison days for William, the 5-minute timer produced superior results than the 60-minute timer, yielding a PND of 83%. For Collins, 10 comparison days produced similar but somewhat weaker results, with the 5-minute timer superior to the 60-minute timer, yielding a PND of 60%. For Lizzy, the results were different. Across 10

comparison days, Lizzy produced superior results with the 60-minute timer compared to the 5-minute timer, yielding a PND of 80%.

### **DISCUSSION**

The results of this study demonstrate that all three children increased their accuracy during a home-based routine after using an LBBI story and self-regulation timer. This study extends the LBBI literature by improving self-care and daily living skills (Brady et al., 2016; Brady et al., 2016), employment skills (Hall Pistorio et al., 2018), first aid skills (Kearney et al., 2018), and prosocial behavior (Keeter & Bucholz, 2012) to children and adults.

Figure 2
Percentage of Correct and Independent Toothbrushing Steps.



Further, these findings build on previous research demonstrating the effectiveness of digital and electronic stories for young children. To date, LBBIs with young children have been an undeveloped area of research, with only one study including timers as a self-regulation intervention (Hall Pistorio et al., 2017). Like the research with children as young as 36 months, the current findings increased young children's self-regulatory behavior after using an electronic LBBI with a timer. These findings also build on a second study in which children mastered kindergarten transition skills (e.g., matching, gluing, and cutting) using electronic LBBIs delivered in small groups (Hall Pistorio et al., 2021). These three studies suggest that digital LBBI stories have robust instructional potential, supporting previous research by Brown (2015), who demonstrated the impact of digital devices on reading engagement and time spent reading for young children.

Although the intervention effectively increased the accuracy of children's toothbrushing at home, it was not clear why two children performed equally well under different (5-minute vs 60-minute) visual timer formats, nor why the third child's performance fell into a range defined by Scruggs and Mastroprieri (2013) as minimally effective. As the first study to compare the impact of different timer formats, we are conservative about evidence suggesting one visual format might be more effective than another, even though the children preferred just one of the formats (the 60-minute timer). It is encouraging that the new skills were maintained for all three children during follow-up, so an LBBI designed to use a self-regulation timer could assist families looking for ways to support their children as they learn essential home care routines.

#### Limitations

Unfortunately, a few factors encountered during this study may have affected the overall findings. First, the observer who conducted agreement and fidelity observations was aware of whether the observations reflected baseline, intervention, or follow-up; it is possible this influenced her scoring. Although not always applied, observers should be blind to the experimental schedule of observations. A second limitation involves the delivery of the LBBI story via iPad. Several investigations have delivered LBBI stories using electronic, enhanced electronic, and paper formats (Kearney et al., 2018; Hall Pistorio et al., 2021). Although mounting evidence shows that electronic story delivery might be more efficacious than other modes, many families need help to afford iPads or similar devices. For such interventions

to make an impact, additional research will be needed on interventions accessible to families of various economic means.

Educators have sought to enhance children's home environments for decades. Children's outcomes in this study are just one of many routines families describe as needing attention. The intervention in this research targeted young children in home environments. As an effective but low-intensity intervention, LBBIs and self-regulation timers might make other families more independent. Additionally, LBBIs could be designed to teach children to use other timing devices, such as watches or auditory cueing systems. While we intend to investigate further the efficacy of timers for young children, we also recognize the potential benefits of this intervention for older children and adults. Investigating self-regulation timers with adolescents with autism spectrum disorders, intellectual disabilities, or other developmental disabilities might improve their access to residential and community settings, school routines, and even employment settings.

The targeted skills in the present study (toothbrushing) are essential for all children to learn, and this type of intervention could be extended to other vulnerable populations, including those at risk due to environmental circumstances, poverty, children in foster care, and others in need of home support. Similar interventions could also be designed for caregivers, with research questions that target generalized outcomes and settings (e.g., home and school). The LBBIs and timers we explored in this study hold promise for other applied researchers.

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#### JIASE SUBMISSION GUIDELINES

# The Journal of the International Association of Special Education (JIASE)

Articles that have not been previously published and are not under review by any other publication and meet the IASE mission statement aims are invited for review. Research articles, articles discussing special education and inclusion policies, and articles for practitioners (PRAXIS) will be given equal consideration.

# Mission Statement of the International Association of Special Education

The aims of the IASE are to promote professional exchange among special educators and other professionals who work with children with disabilities all over the world, to develop special and inclusive education as a discipline and profession, to encourage international cooperation and collaborative international research, to promote continuing education of its members by organizing conferences, and to foster international communication in special and inclusive education through the *Journal of the International Association of Special Education* (JIASE).

#### SUBMISSION GUIDELINES

#### **GENERAL**

Manuscripts with research, policy, and practice content must be relevant to international audiences of researchers, teachers, lecturers, paraprofessionals, parents, and others. Manuscripts that have no clear message for readers in other countries will be returned to the author.

#### **FORMAT**

#### **Style**

Total length of the manuscript is not to exceed 25 pages, double-spaced, and should include all references, charts, figures, and tables. Articles submitted should follow the guidelines of the *Publication Manual of the American Psychological Association* (APA), Edition 7.

#### **Word Processing**

Using American English, manuscripts are submitted in Microsoft Word format using 12 point Times Roman typeface (no bold or italics). The entire document should be double-spaced with .75 inch margins all around (top, bottom, left, and right), with the exception of long quotations (single-spaced). Tables, charts, figures, and/or illustrations should fit in a 3.25 inch-width column and are to be on separate pages at the end of the manuscript. Please attach original tables and figures, not pictures. Additionally, a copy of any photos or illustrations must be attached electronically in a JPEG or similar format. References are to be in APA style with hanging indents.

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#### **PRAXIS Submission Guidelines**

The PRAXIS section of this journal is intended for readers to be able to apply the methods/strategies described in the articles in their classrooms, transition programs or employment settings. These methods/strategies may be new and unique ideas or they can be effective methods/strategies that some teachers have been using, and believe that by sharing them, other teachers can implement them in their practice. The articles should be approximately 7–12 pages, double-spaced, and describe in detail a specific teaching strategy, curriculum or assessment method. The articles should include specific information on how to adopt, adapt, and implement these methods and/or strategies. These articles are to be submitted following the same submission guidelines and will go through the same review process as all JIASE articles. The format for these articles should include an introduction, step-by-step directions, materials/examples of charts or graphs if needed, recommendations, and references.

We encourage you to consider submitting methods/strategies that you have used with students with disabilities and think would be of interest to our readers. Classroom teachers, university instructors, and other professionals working with students, young adults, and adults with disabilities are all welcome to submit articles for consideration for publication in the PRAXIS section of the journal.

#### **General Mailing Address**

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# **IASE 2024**

**JUNE 28 – JULY 1** 

Supporting Inclusion of Persons with Disabilities across the Life Span



# General information

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**International Association of Special Education** 

In Conjunction with

The Faculty of Education,
University of West Bohemia, Czech Republic

**June, 27** 

**Pre-conference Site visits** 

June, 28 - July, 1

Conference

