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A systematic review of bilingual experiences, labels, and descriptions in autism spectrum disorder research

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There is growing research on autism spectrum disorder (ASD) that examines linguistically diverse samples, increasing research generalizability as many individuals with ASD live in bilingual or multilingual communities. However, bilingualism is not a homogenous experience that can be easily categorized. By clarifying participants' language experiences, research findings can be more meaningful for clinicians and practitioners. In this systematic review, we document how the language experiences of samples with and without ASD were described in 103 peer-reviewed journal articles. We observed that language experiences were characterized using a wide range of labels and descriptions. Approximately half of the studies in this review reported participants' language acquisition history, and 64% of the studies defined language proficiency using standardized measures or parental reports. However, <20% of the studies reported daily language exposure and/or usage of the participants. The diversity in how participants' language experiences were characterized in research reflects the complexity of bilingualism. Yet, to further understand how ASD and bilingualism intersect across studies, to facilitate meta-science development, and to balance generalizability with specificity, reporting common characteristics of bilingual experiences is recommended.

KEYWORDS

autism, bilingualism, language experiences, translation, systematic review

1. Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by atypical social communication and interactions, as well as the presence of repetitive and restricted behaviors (American Psychiatric Association, 2013). Prevalence of ASD varies, as reported in the literature, estimated to be 1–2% worldwide (Elsabbagh et al., 2012; Baxter et al., 2015) and 2.3% in the United States (Maenner, 2021). Given the rising number of children who speak multiple languages around the globe (Baker, 2011), the reality is that many children with ASD[1] are currently growing up in bilingual homes or living in

1 Person-first and identity-first language will be used interchangeably to reflect the diversity of preferences in the autism community (Kenny et al., 2016).

bilingual communities (Fahim and Nedwick, 2014). Accordingly, practitioners have raised awareness about bilingual exposure in autistic children's developmental outcomes (Trelles and Castro, 2019). In addition, growing research has examined families that speak two or more languages and their autistic children (Jegatheesan, 2011; e.g., Hambly and Fombonne, 2012; Valicenti-McDermott et al., 2013; Kay-Raining Bird et al., 2016; Hampton et al., 2017). Despite advances in research, there appears to be little consistency in how bilingualism is described in the ASD literature (Gross and Tager-Flusberg, 2022; Prévost and Tuller, 2022), which is further compounded by the heterogeneity of ASD. To assess this complexity, in the current study, we conducted a systematic review of the descriptions of bilingualism in published empirical studies in the ASD literature. By illuminating the variation and nuances in the characterization of bilingualism in ASD research, we aim to underscore the need to utilize more transparent and comprehensive reporting of participant characteristics and their bilingual experiences, which will enhance the generalizability and strengthen the implications of the research findings in the ASD literature to an increasingly linguistically diverse population.

Just as the field's understanding of the causal mechanisms underpinning ASD have evolved [e.g., from "refrigerator mothers" (Kanner, 1943, p. 1943; Bettelheim, 1967; Parker, 2014) to genetic contributions (Vorstman et al., 2017; Joseph, 2018)], so too has the field's understanding of children's other life experiences, such as bilingualism. In the 1920s and 1930s, bilingualism, defined as a linguistic experience of speaking and managing two languages, was seen as a negative experience for children due to the fear of mental confusion (Saer, 1923) and of being "handicapped" in language and cognitive development (Manuel, 1935). However, a large body of research on neurotypical populations has dispelled these misconceptions (e.g., Bialystok, 2011; Bialystok et al., 2012; Byers-Heinlein and Lew-Williams, 2013). Importantly, growing evidence has reported that bilingualism does not negatively affect cognitive and language development of children with ASD (Petersen et al., 2012; Reetzke et al., 2015; Uljarević et al., 2016; e.g., Gonzalez-Barrero and Nadig, 2017).

Despite this research evidence refuting bilingualism's harm, the belief that bilingualism may delay or negatively impact language acquisition in autistic children persists, with several studies finding that parents of children with ASD received professional advice to limit their children's exposure to only one language (Kremer-Sadlik, 2005; Fernandez y Garcia et al., 2012; Kay-Raining Bird et al., 2012; Yu, 2013, 2016; Ijalba, 2016). The recommendations against raising a child with ASD bilingually are likely due to the fact that language delays, or difficulties with language acquisition, are common in individuals with ASD (Tager-Flusberg et al., 2005), which may make some professionals and parents wary of exposing a child with ASD to multiple languages. Consequently, parents raising autistic children reported emotional distress (Fernandez y Garcia et al., 2012) and uncertainty (Kay-Raining Bird et al., 2012) regarding making decisions about language use with their child with ASD, as well as conflicts between professionals' recommendations and parents' views toward bilingualism, as well as families' language use among members (Jegatheesan, 2011; Yu, 2013).

Indeed, bilingualism is a complex, multifaceted life experience characterized by language acquisition history, proficiency, as well as language exposure and use (Robertson, 2009; Grosjean, 2012; Prévost and Tuller, 2022). However, the complex, heterogeneous nature of bilingualism has not been uniformly documented by researchers in general. In a systematic review, Surrain and Luk (2019) reviewed empirical studies that compared bilinguals to monolinguals involving neurotypical children and adults, documenting the labels and descriptors researchers used to characterize the language groups' experiences. Results showed that there was substantial variability in how bilingual (and monolingual) experiences were described. About one-third of the studies (31%) simply referred to participants as "bilingual" without providing details regarding the features of bilingual experiences, such as language proficiency, acquisition history, and language exposure and/or use. In addition, the labels applied to bilingual and monolingual groups ranged from more general (e.g., "fully bilingual") to more specific (e.g., "French-English simultaneous bilingual"). A recent *narrative* review article by Prévost and Tuller (2022) found a similar pattern in the articles on bilingual language development in ASD, with studies using vastly different definitions and characterizations of bilingualism. The variability in the labels and definitions of bilingualism across studies means that individuals who were classified as "bilinguals" in one study could be categorized as "monolinguals" in another study (Prévost and Tuller, 2022). Therefore, the inconsistencies in characterizing bilingualism could result in mixed findings in meta-analyses, in families receiving conflicting recommendations from professionals, and/or in recommendations that clash with unique familial practices regarding the ideal language environment for a family's bilingual child with ASD.

Given the growing research in bilingualism and ASD, a *systematic* review of how bilingualism is labeled and described in the ASD literature is warranted to clarify the language backgrounds of participants, to allow for meaningful interpretation and synthesis of findings, and to ultimately provide evidence-based recommendations and advice about the use of bilingualism for families and practitioners working with autistic children. To date, several reviews have reported different ways in which bilingualism impacts autistic individuals. For example, some researchers have examined whether bilingualism affects language, cognitive, and behavioral outcomes in children with ASD (e.g., Drysdale et al., 2015; Lund et al., 2017; Wang et al., 2018; Prévost and Tuller, 2022), and others have provided recommendations regarding language environments for autistic children (Beauchamp and MacLeod, 2017; Lim et al., 2018). Previous reviews have summarized specific research focusing on the timing of second language acquisition (Kay-Raining Bird et al., 2016), on communication patterns (Dennison et al., 2018), and on ASD and bilingualism in conjunction with other developmental disorders (Goral and Conner, 2013; Kay-Raining Bird et al., 2016; Uljarević et al., 2016). However, there have been no systematic investigations of the specific labels and descriptions of bilingualism in the ASD literature. Further, while Surrain and Luk (2019) took critical first steps in illuminating the need for consistent labels, they opted not to include clinical samples, such as those with ASD. Likewise, Prévost and Tuller (2022) focused exclusively on language development and acquisition, leaving still much to learn about how the ASD literature conceptualizes bilingualism. Thus, the goal of the present study was

to extend the existing line of work by systematically reviewing and characterizing the heterogeneity in the labels and descriptions of bilingualism in the ASD literature. As such, we had three main research questions for this systematic review:

1. What are the characteristics of participants in empirical studies examining the intersection of ASD and bilingualism (e.g., age, sex, sample size)?
2. What terminologies and labels do authors employ to describe bilingualism?
3. Regarding bilingual experiences, what characteristics do authors report (e.g., language acquisition history, proficiency, languages spoken)?

2. Methods

2.1. Search strategy and study selection

We conducted a systematic literature review according to PRISMA guidelines by first searching six databases (ERIC, PsycINFO, Linguistics and Language Behavior Abstracts, Web of Science, Education Abstracts, and Academic Search Premier), using Boolean search methods based on each database's assigned descriptors, titles, and abstracts for keywords related to ASD and bilingualism. Specifically, for bilingualism, we used *bilingual**, *multilingual**, *trilingual**, *"English language learner*"*, *"language learner*"*, *"minority language learner*"*, *"second language"*, *"English as a second language"*, *ELL*, *ESL*, *"limited English"*, *"dual language"*, or *"limited English prof*"* to identify relevant papers. For ASD, our keywords included *autis**, *ASD*, *"autism spectrum disorder*"*, *"autism disorder*"*, *PDD*, *PDD-NOS*, *"pervasive develop*"*, or *Asperger**. As the goal of this systematic review was to thoroughly survey the labels, descriptions, and characteristics of bilingualism in the ASD literature, no time limit was set in the search. Our search yielded 682 papers published through September 2021.

After removing duplicates ($n = 260$), we preliminarily screened the titles, abstracts, and keywords of the remaining 422 papers for possible inclusion of ASD and bilingual samples. From this process, 177 papers were eligible for a full text review and were examined based upon three inclusion criteria: (1) participants were interested parties associated with ASD (e.g., individuals, parents, or educators); (2) at least one group of participants were bilingual (defined as speaking at least two languages to varying degrees) *or* at least one group of participants were direct interested parties in bilingual communities (e.g., Spanish-speaking Latino parents raising children in an English-speaking community); and (3) the papers were published in English, were peer-reviewed (i.e., no book chapters, no dissertations), and empirical (i.e., no literature reviews). One hundred and three papers remained in the final analytic sample, published from December 1984 to August 2021. Figure 1 shows the PRISMA flow chart of the search strategy and study selection procedure.

2.2. Data extraction and coding

Data from the studies were extracted and coded using the following steps. First, we created a codebook to document information from each study. Basic study characteristics, such as author name(s), publication year, setting, and methodology were extracted. Then, additional features of how bilingualism was labeled and characterized were documented. Table 1 presents a condensed version coding scheme with guiding questions and coding values. The authors double-coded 25% of the included studies, with a percent agreement of 94% for coded variables (i.e., excluding variables pertaining to study publication year, journal, or authors as to avoid inflation of the agreement rate). All coding inconsistencies were resolved in follow-up meetings between the coders, in which coders discussed discrepancies and collaboratively determined the correct codes.

In the current study, the key variables of interest were related to bilingualism. To examine how bilingualism was labeled in participants across studies, we first coded whether a study employed *terms* that are commonly used to refer to bilingual experiences (e.g., "bilingual," "English Language Learners"). If authors used any terms that were unique to that study (e.g., "English-proficient bilinguals"), we classified such labels in the "other" category and recorded the exact words from the study. Specifically, we conceptualized "other" terms as descriptions that could not be easily inputted into a database or search bar (e.g., "…participants were native speakers of Mandarin Chinese with basic knowledge of English…"; Tsai et al., 2013, p. 891), as to highlight the challenges in capturing studies using such terminology.

After examining terms describing bilingualism, we coded for *descriptions* regarding bilingualism and bilingual experiences, such as language acquisition history, proficiency, usage, and language(s) spoken to determine how each study qualified the nature of bilingualism (Table 1). We also documented general participant characteristics, such as sample size, average age, and sex. These procedures were modeled following a previous study examining the characterization of bilingualism in nonclinical samples (Surrain and Luk, 2019). To maintain transparency and enhance reproducibility, the complete codebook is available on Open Science Framework (OSF): https://osf.io/gvn93/?view_only=9ed9b6f9ad0d44058cc71340978324fc.

3. Results

3.1. Study and participant characteristics

The coding scheme for participant characteristics, bilingual labels, and descriptions are provided in Table 1. Among the 103 papers, 37 were qualitative (35.9%), 60 were quantitative (58.3%), and six used mixed methods (5.8%). The majority of studies were conducted in North America ($n = 59$, 57.3%), with 46 studies (44.7%) conducted in the United States and 13 studies (12.6%) conducted in Canada. Eighteen studies were conducted in countries in Asia (17.5%), 14 studies were conducted in Europe (13.6%), three studies were conducted in Australia (2.9%), and two studies were conducted in Africa (1.9%). Finally, seven studies (6.8%) included participants from multiple countries (e.g., the United States, Canada, the Netherlands, and the United Kingdom).

To best understand participant characteristics in the studies, we first examined sample size, age, and sex, as well as diagnostic and bilingualism status. Sample size was quite variable, ranging

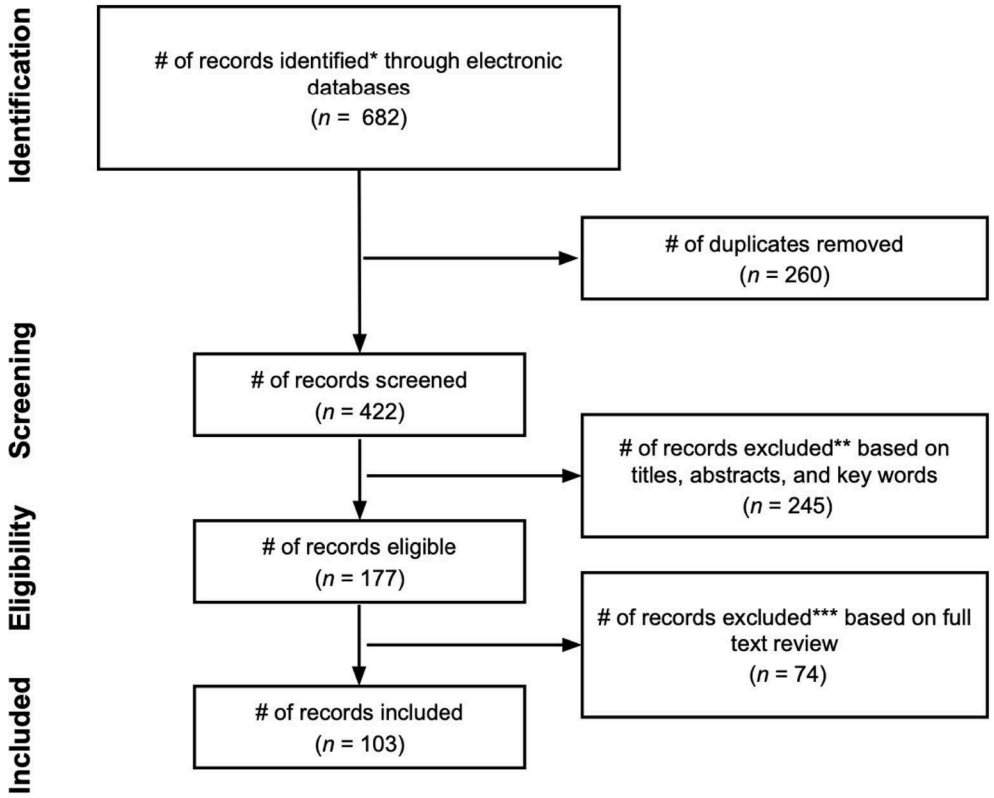

FIGURE 1
Search and identification process for included studies. *Boolean search methods were used to identify the studies (e.g., [autis* or ASD or asperger* or pervasive develop*] and [biling* or multiling* or "language learner*" or "second language"]). **Papers needed to include bilingual and/or autistic samples. ***See "Search strategy and study selection" for a thorough description of the inclusion and exclusion criteria.

TABLE 1 Condensed version of the full coding scheme, which can be found at OSF: https://osf.io/gvn93/?view_only=9ed9b6f9ad0d44058cc71340978324fc.

Variables	Questions	Coding
Summary of coding scheme		
Bilingual Labels	Does the article use one of the following terms to describe non-monolinguals?:	
	English as a Second Language (ESL), English Language Learners (ELL), Bilingual, Trilingual, Multilingual, Minority Language Speakers, Low Proficiency, Dual Language, Bilingually Exposed, Language Learner, Limited English Proficiencies/Abilities/Competencies, Heritage Language/Bicultural/Multicultural, Polyglot, or Other	0 = no 1 = yes (record term(s) used and specify "Other")
Bilingual History	Does an article describe the order in which bilinguals learned their languages, and/or around what age they learned their second language?	0 = no 1 = yes
Bilingual Proficiency	Does the article describe the participants' proficiency of their first and/or second language(s)?	0 = no 1 = yes
Home Usage	Was percent of language use described?	0 = no 1 = yes (record descriptions)
Languages Spoken	What languages did participants speak?	Record first and second languages
Mean Age	Per group (all participants; ASD and bilingual; ASD and monolingual; typically developing and bilingual; and typically developing and monolingual), what was the average age of the participants in months?	Record average age
Number	Per group (all participants, ASD and bilingual, ASD and monolingual, typically developing and bilingual, and typically developing and monolingual), how many participants were included?	Record sample size
% Male	Per group (all participants, ASD and bilingual, ASD and monolingual, typically developing and bilingual, and typically developing and monolingual), what percentage of the sample was male?	Record percent of male participants

from 1 to 346,957 (x= 5,444, s = 39,659). Two studies were particularly large, as they used secondary data (Yamasaki and Luk, 2018; Shifrer and Fish, 2020; n = 195,849, n = 346,957); when excluding these large studies, on average, studies included 69 participants (s = 113). Thirty-seven (35.9%) studies included $n > 10$ participants, while 17 (16.5%) studies included $n > 100$ participants. When considering age, 31 studies did not report the age of their participants (30.1%). Of the studies that did report age, participants were, on average 10.6 years old (range: 1.67–49.8 years), and the majority of participants reported in these studies were 15 years old or younger (n = 62, 86.1%). In terms of sex, 18 studies only included male participants (17.5%), six studies only included female participants (5.8%), and sex was not specified in 13 studies (12.6%). Of the studies that included both male and female participants (n = 66, 64.1%), the participants were 61.2% male, on average (range: 1%−95%).

When considering ASD and bilingualism status, four groups emerged, with some studies including more than one group: ASD with bilingualism (n = 65, 63.1%), ASD with monolingualism (n = 35; 34.0%), non-ASD with bilingualism (n = 27, 26.2%), and non-ASD with monolingualism (n = 20, 19.4%). Sixteen studies included all groups (15.5%), 26 studies included only individuals with ASD and bilingualism (25.2%), while seven studies only included non-autistic bilingual individuals (6.8%; e.g., bilingual parents of children with ASD) and one study included only non-autistic monolingual participants (1.0%; i.e., Spanish speaking parents of autistic children living in an English-speaking country). Twenty-three studies included both autism groups (22.3%), as to compare the impact of language status (i.e., bilingual vs. monolingual) and 13 studies included both bilingual groups (12.6%), as to compare the impact of ASD (i.e., autistic vs. non-autistic).

3.2. Labels and descriptions of bilingualism

Similar to the previous report summarizing the labels and characteristics of bilingual experiences in typically developing populations (Surrain and Luk, 2019), researchers used a wide range of terms to describe bilingual participants (Figure 2). Seventy-five (72.8%) studies used "bilingualism" or "bilingual," and 37 (35.9%) studies used labels that indicated participants' language learning experiences typically associated with school settings (e.g., "English Language Learner [ELL]," "English as a Second Language [ESL]," "English learners," "dual language learner"). Sixteen (15.5%) studies used labels regarding low and/or limited English proficiency, abilities, or competencies, while 13 (12.6%) studies utilized the terms "multilingualism" and "multilingual." Less commonly used terms included "minority language" (n = 10, 9.7%), "trilingual" (n = 6, 5.8%), "bilingually exposed" (n = 5, 4.9%), "heritage language" or "bicultural"/"multicultural" (n = 5, 4.9%), and "polyglot" (n = 1, 1.0%). Participants were uniquely labeled in nearly one-third of studies (n = 31, 30.0%), which were coded as "other" in Table 1. For instance, Howard et al. (2019) described "English as an additional language," while Chambers et al. (2018) referred to their participants as "second-language English speakers." The majority of studies (n = 60, 58.2%) used multiple labels (e.g., "bilingual" and "English Language Learner"), averaging 1.93 terms and ranging from one to five terms. Of the studies that used more than one term to describe their participants' language experiences, 14 (13.6%) did not use the label "bilingual". Two studies (1.9%) only used labels that were coded as "other" in Table 1 (e.g., "exposed to both Spanish and English in the home environment"; Padilla Dalmau et al., 2011, p. 3).

3.3. Characteristics of bilingual experiences

After examining bilingualism terminologies, we investigated whether studies provided homogeneous descriptions of their participants' bilingual experiences. Consistent with previous research (Gonzalez-Barrero and Nadig, 2018; Surrain and Luk, 2019), we examined language acquisition history, proficiency, home usage, and language(s) spoken. Across these studies, approximately half of the studies (n = 56, 54.4%) reported language acquisition history, such as the age of first or second language exposure and the order of languages learned. For example, Ohashi et al. (2012) wrote that their participants were "simultaneous language learners who were exposed to two languages, one of which was English or French, before the age of two" (p. 892). Of the studies that noted language history, 22 (40.0%) studies included a specific age at which their participants were exposed to their second language. For instance, Iarocci et al. (2017) described the language history of their participants as "for the ASD SE [second language exposure] group the average age was 1.04 years (range = 0–7.50 years), [and] for the TD SE group the average age was 2.64 years (range = 0–8.50 years)…" (p. 1823). Four studies (3.88%) indicated the age of second language exposure with age ranges, which varied from specific [e.g., birth to four years of age, Gonzalez-Barrero and Nadig, 2019a, p. 3893; "English as a second language (ESL) school curriculum begins in the first year of junior high school when students are usually 12 or 13 years old," Omori et al., 2011, p. 11] to broad (e.g., "Ages of acquisition for the second language ranged from 0 to 46 years," Digard et al., 2020, p. 2171). Other studies (n = 10, 9.7%) provided a context in which participants became exposed to their second language (e.g., "Allan was enrolled in Norwegian speaking kindergarten when he was 5 years-old… His home language was not Norwegian," Özerk and Özerk, 2015, p. 90). These language exposure contexts were primarily based in schools rather than in homes.

Furthermore, we found that 64% of the studies (n = 31, 30.1%) reported language proficiency using standardized assessments (e.g., Peabody Picture Vocabulary Test, 4th edition, Dunn and Dunn, 2007), as well as parent ratings, as in Gonzalez-Barrero and Nadig (2017, 2018). Most notably, fewer than one-fifth of the studies (n = 18; 17.5%) quantified the degree to which participants used or were exposed to each language. Zhou et al. (2017), for example, specified that their bilingual participants had "exposure to one language other than English 20% or more of the time," whereas "English was spoken at least 90% of the time" for their monolingual participants

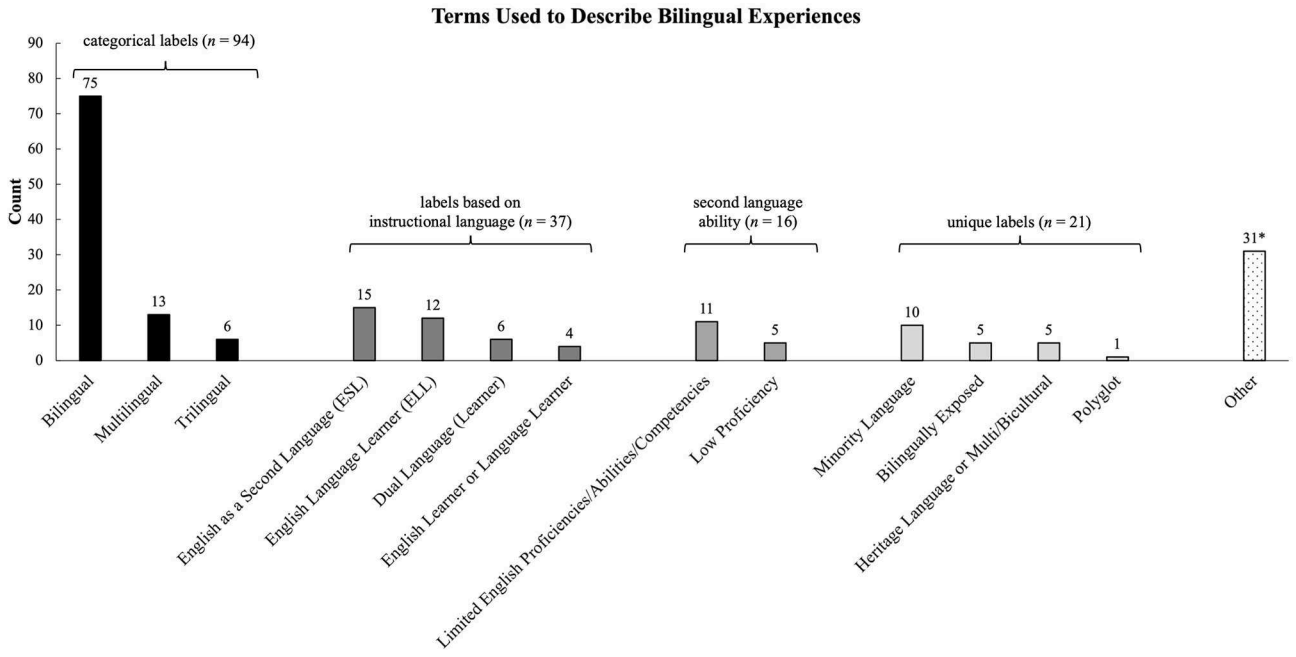

FIGURE 2
*"Other" terms included the following descriptions: "second-language English speakers," "all of them had an exposure to English through nursery rhymes," "exposed to Spanish and English in the home environment," "multiple languages in the workplace," "...parents spoke a primary language other than English in the household," "limited or non-English competencies," "not native English speakers," "proficient bilingual children," "English was not the primary language spoken at home," "English as secondary language learning and teaching process," "was exposed to more than one language on a daily basis," "English as an Additional language (EAL)," "English as a second/non-native language," "second language exposure (SE)," "bilingual English and Spanish," "home language," "English not primary language at home," "culturally and linguistically diverse (CLD)," "non-English speaking families," "a native language other than the majority language," "obligatory bilinguals," "exposure to two or more languages at home," "mother-tongue at home," "two or more additional languages," "native language," "native speakers of Mandarin Chinese with basic knowledge of English," "a bilingual child was defined as a child who was exposed to both English and Spanish at home, regardless of their expressive or receptive abilities in either language," "bilingual English-Spanish," "more than one language spoken at home," "emerging bilinguals," "English-proficient bilinguals," "who come from a home that speaks any language other than English," "Chinese-English bilingual children," "families who speak more than one language," "home language environment/HLE," "dual-language home environment," BLH (bilingual home environment), and "spontaneously acquired the English language".

(p. 3). However, (Sendhilnathan and Chengappa, 2020a,b) defined their monolingual participants differently, "A participant was considered monolingual if she/he used English language more than 80% of the time (including school and home)" (p. 72, 52 respectively). Alternatively, some studies simply provided a range of language exposure. For instance, Gonzalez-Barrero and Nadig (2018) noted that their "participants' current amount of exposure to French… ranged from 6% to 99%." (p. 3).

4. Discussion

With the growing linguistic and cultural diversity among children with ASD, it is important to examine the current state of research intersecting bilingualism and ASD. In this systematic review, we analyzed how researchers reported labels and descriptions of bilingualism, as well as participants' bilingual experiences, in 103 published peer-review articles in the ASD literature. Similar to previous research, we identified great variability among bilingualism labels and descriptions, as well as among bilingual experiences.

4.1. Study and participant characterization

To begin, patterns in the study and participant characteristics revealed meaningful gaps in the current ASD literature regarding bilingualism. Few studies specifically defined bilingualism (Ohashi et al., 2012; Zhou et al., 2017; Hoang et al., 2018; Sendhilnathan and Chengappa, 2020a,b; Sharaan et al., 2021; e.g., exposed to a second language ≥20% of the time: Gonzalez-Barrero and Nadig, 2017, 2019b). Similarly, some studies utilized participants' self-reported bilingual experiences, which may have introduced the possibility that the participants' sociolinguistic context of their community impacted how they saw themselves linguistically. Language experience inherently reflects the community in which a language is spoken. While most studies occurred in one country, thereby minimizing (but not eliminating) sociolinguistic variability, 6.8% of studies occurred across multiple countries, introducing more variability regarding how bilingualism is perceived among the participants *within* the studies. Without providing a study-based operational definition of bilingualism, results may be challenging to generalize across contexts or communities.

Surprisingly, nearly one-third of studies did not report the age of their participants. Considering language trajectories in both ASD (Pickles et al., 2014; Tek et al., 2014; Gernsbacher et al., 2016)

and typical development (Visser-Bochane et al., 2020), without reporting age, the field is unable to meaningfully apply those studies' findings. Though children and adolescents with ASD have variable language development trajectories (Gernsbacher et al., 2016), reporting chronological age facilitates a more complete understanding of a sample's characteristics, as well as what language skills may be expected from a developmental perspective. Given the conflicting guidance parents of autistic individuals are receiving, the specificity of findings is crucial because it will better enable clinicians and practitioners to know for whom research is relevant, which in turn should help better align research and practice. This alignment is only possible when researchers report key participant characteristics. Of the studies that did include age, participants were relatively young, such that the bulk of research focused on adolescents or younger children ($\leq$ 15 years of age; 86.1%). While it is important to examine language earlier in development due to developmental trajectories (Iverson, 2021; Bradshaw et al., 2022), autistic individuals' age and the lack of information in older age brackets (e.g., >15 years of age) represents yet another way in which the ASD field is lacking knowledge about the transition to adulthood (Magiati et al., 2014; Howlin and Magiati, 2017). Further, independent living is a key research topic for individuals with ASD as they emerge into adulthood (Ivey, 2004; Farley et al., 2009; Henninger and Taylor, 2014; Matthews et al., 2015; Thompson et al., 2018; Pillay et al., 2022). In countries in which more than one language is spoken or in which a language that is different from an individual's home language is common, an understanding of bilingualism in older autistic individuals is paramount to paint a complete picture of what independent living requires of autistic adults.

4.2. Bilingualism characterization

Regarding the terms and labels used to describe bilingualism in the ASD literature, there was substantial variability. In all the studies included in this systematic review, "bilingual" or "bilingualism" was the most common term (72.8%), but this was followed by several descriptions of language learning experiences (e.g., ELL, ESL; 35.9%), "other" terms (30.0%), descriptions relating to second language proficiency (15.5%), and then six other categories of discrete terms (e.g., "minority language," "multilingual," "polyglot"; 38.8%), each represented in 12.6%-1.0% of the papers. Notably, a substantial number of studies created their own terms, operationalizing the bi/multilingual experience specific to each study's participants. The broad range of terms is consistent with Surrain and Luk's (2019) findings regarding the characterization of bilingualism in typically developing populations, suggesting that bilingualism is variably operationalized in extant literature in both nonclinical and clinical populations. More pressing than broad operationalization, the terms describing bilingualism may be inconsistently operationalized across studies. Of the 16 studies that used the terms low and/or limited English proficiency, abilities, or competencies, only five (31.3%) studies also described the actual English language proficiency of their participants. Moreover, when describing participants' language proficiency in relation to their English language abilities, little attention was simultaneously paid to their heritage language background and proficiency, creating opaqueness regarding their overall language abilities. These discrepancies highlight the challenge of balancing generalizability with specificity. While it is important to use descriptions that apply to broad categories of experiences, lack of specificity may lead to (a) challenges in confirming the validity of group categorization; (b) challenges in translating findings from research to relevant populations; and (c) difficulties in aggregated analyses, such as meta-analyses, particularly ones examining group comparisons between bilinguals and monolinguals. While it is not realistic to expect to have a universal term for bilingualism, it is important that researchers report consensual constellations of factors relevant to bilingualism (e.g., Byers-Heinlein et al., 2019) to support and facilitate meta-analyses and syntheses, as well as use consistent characterizations across studies.

A substantial portion of the studies also lacked comprehensive descriptions of the language backgrounds and language abilities of their participants, such as proficiency, history, and home usage. For instance, only about two-thirds of the studies reported language proficiency of participants using standardized assessments or parent ratings. While language proficiency may not be a key variable of interest in all studies, it is still important to assess and provide information about language proficiency to justify and characterize samples. As with the concern for differently operationalized terms for bilingualism, reporting language proficiency enables the field to more accurately synthesize, apply, and replicate findings by ensuring that the participants in the research settings match the language proficiency profiles of individuals in other or future studies, as well as in "real world" (e.g., clinical, practice, educational) settings. Further, from a theoretical standpoint, language ability is not singular; there are many ways in which an individual can demonstrate language ability. For example, in studies on typical developing samples, in comparison to their monolingual peers, bilingual children tend to show smaller vocabularies when tested in one of the two languages they know, but they show similar performances when tested on conceptual vocabulary (i.e., the representational understanding of a word in at least one language, Core et al., 2013; Gross et al., 2014). Collectively, these studies illustrate how clear differences in language profiles arise when language proficiency is measured differently, further highlighting how specificity is important in the pursuit of research synthesis, replication, and application. Without reporting participants' knowledge and repertoire in each language, and the ways in which they are proficient, researchers and practitioners will continue to have an incomplete understanding of how ASD and bilingualism intersect.

Further demonstrating the current incomplete picture of ASD and bilingualism, only a subset (17.5%) of the studies provided language acquisition history and bilingual usage or exposure. Given the accumulating evidence that language acquisition history and exposure are associated with language proficiency, as well as with vocabulary and morphological skills of children with ASD (Hambly and Fombonne, 2014; Gonzalez-Barrero and Nadig, 2018), this paucity of reporting shows a substantial missed opportunity

to better understand language development of bilingual autistic children. More importantly, this dearth of information is another example of the ways in which some findings on bilingualism and ASD are not fully realized. Language experiences are diverse across individuals and across communities; for instance, a person who grows up speaking Spanish at home and English at school will have a distinct bilingual experience from someone who moves to a foreign country in adulthood and then learns a second language. Bilingualism is not uniform, so researchers ought to describe the degree to which participants are exposed to their second or additional language(s), thereby facilitating research synthesis and knowledge translation.

A striking example of the importance of specifically operationalizing language experience can be seen when comparing Zhou et al. (2017) with (Sendhilnathan and Chengappa, 2020a,b). Zhou et al. (2017) required monolingual participants to speak English at least 90% of the time, while (Sendhilnathan and Chengappa, 2020a,b) used 80% as the minimum amount of English exposure for their monolingual participants. This means that an individual who spoke English 80% of the time could be considered a monolingual in Sendhilnathan and Chengappa, 2020a,b's study but not a monolingual in Zhou et al. (2017)'s study. Neither study's definition of monolingualism is inherently right or wrong, but what is critical is that they both *specifically defined* monolingualism. As such, future researchers can make informed decisions about how to appropriately synthesize their findings. Like Zhou et al. (2017) and (Sendhilnathan and Chengappa, 2020a,b), we recommend that future studies use specific percentages (e.g., exposed to a second language >20% of the time, exposed to English 80–90% of the time), not categories (e.g., exposed to English "most of the time"), to define their participants. Relatedly, participant descriptions did not consistently include the second language(s) spoken by their participants. Recognizing both the dominant and minoritized languages spoken by participants is the first step in describing participants' language experiences. Given the misalignment between research and practice regarding families being told to not expose their child to a second language, despite the lack of evidence regarding negative outcomes, care must be taken to respect, recognize, and honor language diversity.

In sum, the extant literature has used a wide range of labels and descriptions of bilingual experiences in ASD research. This variability both highlights the represented language diversity in the ASD literature and limits the generalizability of findings, making meta-science investigation challenging. In addition to the demonstrated language diversity, the inconsistent reporting of bilingualism characteristics makes the generic description "bilingual individuals with ASD" opaque. For clinicians, this opaqueness in participant characteristics obscures research-practice translation. Moreover, there are conflicts between research, practice, and family values wherein research demonstrates that bilingualism is *not* problematic (e.g., Gonzalez-Barrero and Nadig, 2017), families are being told by practitioners to not use a second language (e.g., Ijalba, 2016), and families report that using their native language brings a sense of emotional connection and community support (e.g., Fernandez y Garcia et al., 2012; Hampton et al., 2017). This conflict appears to create uncertainty for parents, as some families receive English-only recommendations from practitioners even though they themselves may view bilingualism as important or that family members may not have English proficiency to communicate emotional or technical information to their children (Fernandez y Garcia et al., 2012; Yu, 2013; Ijalba, 2016). Moreover, when only using English, family members have reported feeling emotionally distant from their children, expressing that they did not know how to communicate to their children in English. This isolation appears to extend outside the immediate home as well, as some families report that their family became removed from their non-English speaking social, cultural, and familial supports when they implemented English-only practices (Fernandez y Garcia et al., 2012). Further, qualitative studies suggest that this emotional distress may be heightened by parents' feelings of guilt and blame for their child's diagnosis (Fernandez y Garcia et al., 2012; Yu, 2013), as well as by fear that their home language practices were harmful (Fernandez y Garcia et al., 2012), and by the contrasting belief that bilingualism can provide invaluable benefits (Jegatheesan, 2011; Kay-Raining Bird et al., 2012; Yu, 2013; Kim and Roberti, 2014; Hampton et al., 2017; e.g., cultural awareness, future job opportunities, preserving familial relationships). To effectively mitigate this tension, to facilitate transdisciplinary research wherein bilingual home environments have not been shown as harmful, and to be sensitive toward families' values, care should be taken to thoughtfully characterize participants' language backgrounds.

4.3. Limitations and future directions

While this systematic review highlights the current state of research on the intersection of autism and bilingualism, this intersecting field is still in its infancy. Because this review only examined studies published in English and because many of the reviewed studies were conducted in countries in which English is the primary social dominant language, it is possible that some relevant articles were not included (e.g., those published only in Spanish) and that the included papers were unintentionally Anglocentric. Given the multilingual nature of the topic, future reviews could aim to include articles published in non-English languages as well to gain a more comprehensive and linguistically diverse representation of bilingualism and ASD. Moreover, this review only included peer-reviewed journal articles, thereby excluding dissertations, chapters, and unpublished sources. As this area is fast-growing, it is possible that we have missed data, findings, patterns, and terminology by excluding non-peered-reviewed publications. Further, one demographic factor related to bilingualism is socioeconomic status (SES). We initially had SES as a coding element but were not able to complete coding due to the lack of information in the studies. Future research would benefit from attending to other social correlates of bilingualism, such as SES, so that they can be examined in future analyses. Finally, it is important to acknowledge that this is an evolving field; as the field increases its understanding of what variables are informative (e.g., amount of second language exposure), future reviews should embrace newer variables by including and reporting them.

4.4. Conclusion

While there has been an increase in the number of studies that examine ASD and bilingualism and while previous reviews have sought to characterize specific facets of this intersection (e.g., communication patterns, Dennison et al., 2018), our systematic review aimed to broadly detail the research junction of ASD and bilingualism. In doing so, we found substantial variability in the labels and terms used to describe bilingualism. Moving forward, research will need to balance generalizability and specificity of participants' individual or cultural experiences. While consistent terminology and clear reporting of bilingual characteristics will be important in applying findings, given the vast number of languages in the world, it is unlikely that every individual's language experience will be represented in the literature (e.g., in our review, no papers reported that their participants spoke Yiddish). When generalizability cannot be achieved, explicit descriptions of participant characteristics are a necessity. In line with Byers-Heinlein et al. (2019), we recommend that future studies thoroughly characterize the language experiences of their participants by explicitly reporting language history, use/exposure, and proficiency of all languages spoken, as well as the languages spoken by their participants, taking care to clearly describe how bilingualism is operationalized in their study so that the field can move forward with a clearer understanding of how bilingualism and ASD impact each other.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Author contributions

RH, BC, and GL contributed to the conceptualization of this review. RH, BC, KH, and ZN coded and reviewed the papers, with RH and BC organizing data management and facilitating coding consensus. RH and BC wrote the manuscript, with GL providing guiding feedback. GL contributed to funding acquisition. All authors contributed to the manuscript revision process, as well as approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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