

Parental experiences raising children with autism spectrum disorder in Eastern Europe: a scoping review

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Parents of children with autism spectrum disorder (ASD) are often at greater risk of experiencing stress and lower quality of life, in comparison to parents of typically developing (TD) children and other developmental disabilities. Despite vast literature on parental experiences in Western countries, little is known about this topic in Eastern Europe. Thus, we aimed to map studies that addressed parental experiences of children with ASD in Eastern Europe using the Double ABCX theoretical framework. The Double ABCX Model of family adaptation describes how families responds to stressors over time, based on the intercorrelation of available resources, coping mechanisms and appraisal of stressors. Following a scoping review methodological framework, we conducted a comprehensive search of three databases. We ultimately included 15 peer-reviewed studies in the review. Within each study, we examined Double ABCX Model factors. The studies were conducted in nine Eastern European countries and included parents of children and adults with ASD. Consistent with studies conducted in Western countries, parents of children with ASD expressed more personal and family challenges and greater maladaptation compared to parents of TD children. Moreover, families reported lower satisfaction with quality of life and more health problems. The small number of included papers from nine countries suggests that parental experiences of children with ASD in Eastern Europe are overlooked in the literature. Future research should explore findings from this review that differed from the Western literature, including contributing factors to parental adaptation in families in Eastern Europe.

Keywords: Eastern Europe, Double ABCX Model, autism spectrum disorder, parents, stress, quality of life

Introduction

Autism Spectrum Disorder (ASD) is characterized by impairments in social communication and the presence of restricted or repetitive behaviors (World Health Organization 2018). Parents raising a child with ASD are at higher risk of experiencing elevated levels of general stress and parenting distress (Baker-Ericzen *et al.* 2005, Lee *et al.* 2009, Brobst *et al.* 2009), even when compared to families of children with other intellectual and developmental disabilities, such as Down syndrome (DS; Hartley *et al.* 2012, Hayes and Watson 2013). In addition, parents of children with ASD report increased symptoms of anxiety and depression (Phetrasuwan 2003). Compared to parents of typically developing (TD) children, parents of children with ASD report lower rates of marital satisfaction and lower perceived quality of life (Brobst *et al.* 2009, Lee *et al.*

2009); and fewer adaptive coping skills (Lee *et al.* 2009). Despite facing many challenges, studies have found families of children with ASD are resilient and able to cope and positively adapt (Manning *et al.* 2011). Moreover, some families show positive experiences and gains raising children with ASD (Bayat 2005, Russell and Norwich 2012).

Double ABCX Model overview

The Double ABCX Model examines processes of appraisal, coping and adaptation to stressful situations over time (Lavee *et al.* 1985, McCubbin and Patterson 1983). Because of their children's many changing needs, families of children with ASD must frequently adapt: first to their child's diagnosis, and then to their child's needs and behaviors as they age (Manning *et al.* 2011). The Double ABCX Model provides a framework to conceptualize the factors contributing to parental stress and distress, as well as the ways in which individuals and family systems appraise, respond, and cope

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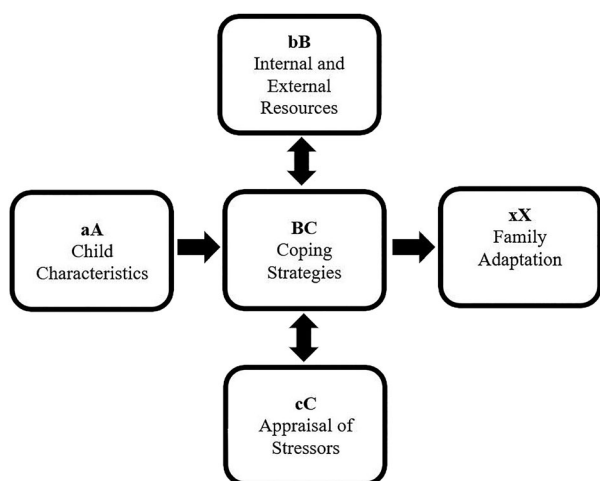


Figure 1. The modified Double ABCX model (based on McCubbin and Patterson 1983).

to stressors (see Figure 1). Notably, the Double ABCX Model includes post-crisis variables, which are critical in order to assess family adaptation over time.

The Double ABCX Model starts with an initial stressor, “a”, which refers to an event or condition that occurs, such as a child’s diagnosis. The initial stressor is compounded by a “pile-up” of additional stressors (aA), which can include challenging child characteristics, service needs, or financial concerns. Families’ existing resources (“b”), along with new resources developed to address the initial crisis (“B”), impact the way in which they adapt and respond to current stressors. Resources can be internal (e.g. knowledge) or external (e.g. social support). Families’ appraisal of stressors (aA) and resources (bB) is the “cC” factor. Together, families’ resources (bB) and perceptions (cC) impact the way in which the family copes (BC), as well as how they ultimately adapt (xX). The xX factor can be conceptualized as either an “outcome” or a “process.” Some families have a positive outcome (bonadaptation), in which families effectively changes their roles, routines and other interactions to accommodate the new demands. On the other end of the continuum, the xX factor can refer to negative adjustment (maladaptation) to the aA factor, which leads to the family experiencing a crisis (McCubbin and Patterson 1983, Pozo et al. 2014).

Double ABCX Model factors in ASD research

Extant ASD research has extensively described stress among families raising children with ASD. Bristol, a pioneer in the field, used the ACBX Model to predict depression, marital adjustment and quality of parenting among mothers of children with ASD (Bristol 1987). We briefly describe the relevance of ASD research findings to the Double ABCX Model below.

aA factor: child characteristics

The severity and symptoms of ASD can themselves be stressors. Parents of children with more severe cognitive, language/communication, and social impairments experience higher levels of stress and symptoms of depression (Benson 2010, Osborne et al. 2008, Stuart and McGrew 2009). In particular, the literature has focused on challenging behaviors, including conduct problems and self-injury, as these behaviors are associated with higher levels of parenting stress and psychological distress (Lecavalier et al. 2006, Paynter et al. 2013).

bB factor: internal and external resources

Parents of children with ASD with higher self-esteem experience fewer depression symptoms (Paynter et al. 2013, Weiss 2002). Further, parents of children with ASD with an internal locus of control, strong sense of purpose, and commitment to their values experienced less stress (Weiss 2002, Siman-Tov and Kaniel 2011). Moreover, optimism is linked to overall well-being and fewer depressive symptoms (Ekas et al. 2010). External sources of support, such as social and spiritual support, are associated with reduced parenting stress and better family functioning and quality of life (Bristol 1987, Manning et al. 2011, Weiss 2002). Conversely, parents with little perceived spousal, family, and other social support experience higher levels of stress, depression, anxiety, and anger (Boyd 2002).

cC factor: appraisal of stressors

The way in which a family understands and defines their child’s needs can impact their adaptation to stressors. Families that positively reframe stressful situations experience improved family functioning, higher quality of life and less parental distress (Bayat 2005, Manning et al. 2011). On the other hand, parents who negatively view having a child with ASD experience reported higher levels of burden (Stuart and McGrew 2009).

Researchers have extensively studied sense of coherence (SOC), or the extent to which one believes events are comprehensible, manageable, and worthy of engagement (Antonovsky 1987). In the ASD literature, higher parent SOC is associated with less stress (McStay et al. 2014), as well as seeking social support, adaptive coping, positive family quality of life, and psychological well-being (Paynter et al. 2013).

BC coping strategies

Family coping strategies are depicted in the Double ABCX Model as the interplay between stress appraisal (cC) and resources (bB). Parents of children with ASD that use active–avoidance and passive-avoidance coping strategies, experience higher levels of depression, stress, poor psychological well-being, and marital/family burden (Pozo et al. 2014, Stuart and McGrew 2009).

Conversely, parents using confrontational, problem-focused coping styles report less depression and burden (Dunn *et al.* 2001, Stuart and McGrew 2009).

ASD in Eastern Europe

Despite an abundance of research on the experiences of families raising children with ASD in the United States (US) and Western Europe, the literature from other parts of Europe is limited and ASD prevalence in most Eastern European countries is still unknown (Preece *et al.* 2017). Accordingly, overall knowledge about ASD is low among Serbian middle school students (Čolić 2016), Cypriot college students (Demirok and Baglama 2015) and Macedonian employers (Stankova and Trajkovski 2010). Diagnostic assessments, interventions, trained therapists, and parent support for ASD are similarly limited in the region, leading to children with ASD waiting for several months for an initial specialist visit (Krsmanović *et al.* 2017, Preece *et al.* 2017). Furthermore, given the majority of clinics are located in large urban areas, access is often restricted to families who live in cities or who have enough financial resources (Preece *et al.* 2017). Thus, there is a lag between parents' first concerns and ASD diagnosis, and families primarily cover treatment expenses by themselves (Krsmanović *et al.* 2017).

Thus, we scoped the current literature related to the parenting experiences of families raising children with ASD in Eastern Europe. Using the Double ABCX Model as a guiding framework, we sought to understand the specific stressors facing families of children with ASD in the region, and the ways in which they address and adapt to these stressors in their family systems.

Methods

Overview of search strategy

We performed the study following guidelines for methodological scoping reviews (Arksey and O'Malley 2005). A reference librarian searched PsycINFO, Scopus and Ovid Medline from inception to November 2018. We did not apply search filters in any database. In order to be inclusive, we broadly searched using the following terms: developmental disabilities, ASD, well-being, quality of life, coping, stress, burden, family functioning, resiliency, experiences, family, parents, and caregivers. After our initial broad search, we reviewed titles and abstracts manually, using the study selection criteria below. Finally, we searched the gray literature via Google Scholar using the same combinations of words used for the database literature search.

Study selection

To be included, studies needed to: (1) report on the experiences of parents and other primary caregivers of children with ASD, (2) be empirical, peer-reviewed

research, and (3) be conducted in Eastern Europe. Currently, there is no unanimous agreement regarding countries that constitute Eastern Europe. For the purpose of this review, we focused on former communist countries located in Eastern and Southeastern Europe (Varblane and Mets 2010). We excluded studies not written in English, Serbian, or Croatian, languages spoken by our research team. We also excluded papers examining interventions, as the focus of these studies were not on parents' experiences.

In total, we retrieved 70 references after removing duplicates (see Figure 2 for PRISMA flowchart; Moher *et al.* 2009). Two reviewers scanned titles and abstracts to assess they met eligibility criteria: 13 studies were unavailable in English, Serbian, or Croatian; and 44 were outside of our study aims. The first author was the only reviewer of articles in Serbian or Croatian. After reviewing the titles and abstracts from our Google Scholar and ResearchGate review, we identified an additional three articles. We further excluded one article after the full-text review, due to the article focusing on an intervention. Then, the first and third authors extracted data from the remaining 15 articles (study aims, methodology, measures, summary of findings). These authors, in consultation with the second author, mapped each article onto the Double ABCX model.

Results

Nearly half of the 15 included studies originated from Poland (42.86%), followed by Serbia (21.43%), Croatia (14.29%), North Macedonia (7.14%), Romania (7.14%), and Slovenia (7.14%; see Table 1). One study was carried out in four countries (Croatia, Albania, Bulgaria, and Turkey). Thirteen papers were written in English, and two in Serbian (Milačić-Vidojević 2008, Rudić *et al.* 2013). The majority of the studies used cross-sectional designs ($n = 13$); one study conducted a retrospective review of existing assessment data (Rudić *et al.* 2013); and one study was qualitative (Lisak *et al.* 2017).

Study samples

Six studies included only families of children with ASD; four studies compared parents of children with ASD and TD children; one included families of children with ASD and DS; one compared families of children with ASD and other developmental disabilities; two included families of children with ASD, other developmental disabilities, and TD children. The qualitative study included parents of children with various developmental disabilities, but we focused on the results from families of children with ASD only. The sample sizes of parents of children with ASD ranged from 3 to 759 caregivers (see Table 1).

Nine studies included both fathers and mothers in the samples; one included fathers only; and two

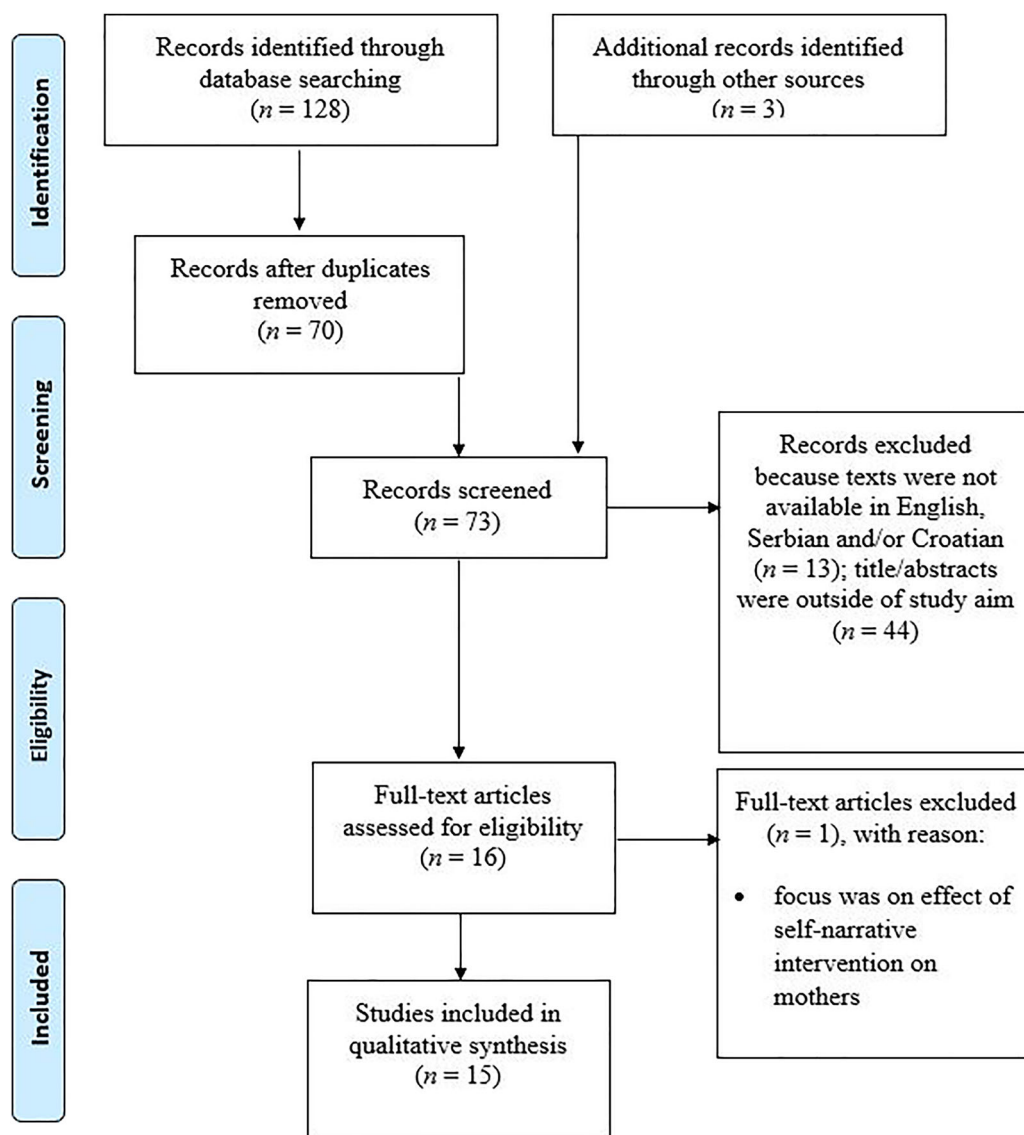


Figure 2. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram.

included only mothers (see Table 1). One study included mothers, fathers, and other primary caregivers (e.g. grandparents), but did not separate provide percentages of each group in their quantitative analyses (Troshanska et al. 2018). The remaining two studies did not provide information about participant gender.

The ages of the parents of children with ASD ranged from 25 to 84 (see Table 1). Four studies did not report sufficient information about parents' age, while four provided only mean ages for each parent group. The ages of the individuals with ASD ranged from 2 to 20 years old, except in Benjak's study (2011) where the oldest individual with ASD was 45 years old. Three studies did not report child age, while three reported only a mean value of child age.

Double ABCX Model factors

Below, we summarize results based on Double ABCX model factors: pile-up stressors (aA); adaptive resources (bB); perception and sense of coherence (cC); coping (BC); and adaptation (xX).

Pile-up stressor (the aA factor)

Eight studies discussed specific stressors impacting families of individuals with ASD. Three studies (Dabrowska and Pisula 2010, Pisula 2007, Pisula and Porębowicz-Dörsmann 2017) measured parent-reported stressors, including child-related challenges (e.g. difficult personality characteristics), a personal parent problem (e.g. excess time demands), and family difficulties (e.g. financial stress). Mothers of children with ASD disclosed more child-related stressors compared to mothers of children with DS (Pisula 2007); while parents of children with ASD reported more child-related, personal, and family challenges in comparison to families of TD children (Dabrowska and Pisula 2010, Pisula and Porębowicz-Dörsmann 2017). Specifically, mothers reported that their child displayed greater social obtrusiveness, difficult personality characteristics, disengagement in activities (Pisula 2007), and dependency (Dabrowska and Pisula 2010). Studies reported mixed results related to physical skills: Pisula (2007) found that mothers of children with ASD

Table 1. Summary of study characteristics, instruments, focus, and double ABCX model factors.

Study, country of the study	Sample	Parent ages –Years (range and/or mean)	Child ages – Years (range and /or mean)	Instrument	Focus of the study	Double ABCX Model Factors
Benjak (2011), Croatia	178 parents of children with ASD and 169 parents of TD children	ASD 28–84 (M = 46); TD 25–83 (M = 45)	ASD 3–45 (M = 15); TD 2–47 (M = 14.6)	1. Personal Wellbeing Index; 2. Self-Assessment of General Health	The aim of this study was to assess subjective quality of life (SQoL) and general health status in parents of children with ASD; and to explore if their SQoL differs from SQoL in parents of TD children.	xx <i>Family Adaptation</i> – Subjective QoL; xx <i>Family Adaptation</i> – Perception of General Health
Dabrowska (2008), Poland	37 fathers of children with DS; 31 fathers of children with ASD; 30 fathers of children with CP; 32 fathers of TD children	DS M = 38.5; ASD M = 40.3; CP M = 41.9; TD M = 38.3	DS 1–22 (M = 9.9); ASD 2–20 (M = 8.1); CP 2–21 (M = 11.2); TD 1–20 (M = 8.2)	1. The Sense of Coherence Questionnaire (SOC-29); 2. Coping with Stress Questionnaire (WCQ)	The aim of this study was to explore relationship between SOC and coping style among fathers with children with DS, ASD, CP and TD children.	cc <i>Perception and Coherence</i> – SOC; bc <i>Coping Strategies</i>
Dabrowska and Pisula (2010), Poland	51 parents of children with ASD; 54 parents of children with DS; 57 parents of TD children	Mothers ASD 25–42 (M = 30.7), Fathers ASD 28–41 (M = 34.4); Mothers DS 25–43 (M = 32.8), Fathers DS 26–44 (M = 34.9); Mother TD 25–43 (M = 31), Fathers TD 27–40 (M = 34.6)	2–6	1. Questionnaire of Resources and Stress (QRS) for Families with Chronically Ill or Handicapped Members-Short Form; 2. Coping Inventory for Stressful Situations	The aim of this study was to examine stress profiles among parents of children with ASD and DS and to compare their reported stress to parents of TD children. Also, the study examines the relationship between parental stress and coping style.	aA <i>Pile up</i> – Child Problems; aA <i>Pile up</i> – Financial Stress; aA <i>Pile up</i> – Limits on Family Opportunity; aA <i>Pile up</i> – Personal Burden; BC <i>Coping Strategies</i> ; xx <i>Family Adaptation</i> – Family Disharmony
Daniels et al. (2017), Albania, Croatia, Bulgaria, Turkey	Caregivers of children with ASD.; 758 (191 from Albania; 147 from Bulgaria; 146 from Croatia; and 274 from Turkey); 603 mothers, 138 fathers and 16 grandparents or others caregivers	Not stated	2.1–18.5 (M = 8.1)	1. Characteristics of the Child with ASD; 2. Service Encounters; 3. Caregiver Needs and Perceptions	The study aimed to obtain initial findings about caregiver needs, their perception about services and service utilization in Albania, Bulgaria, Croatia, and Turkey.	aA <i>Pile up</i> – Financial problems; bB <i>External support</i>
Kasprzak et al. (2013), Poland	31 mothers of children with Asperger syndrome and 31 mothers of TD children	Mothers ASD 31–52 (M = 40); Mothers TD 29–54 (M = 39)	Not stated	1. Polish Resiliency Assessment Scale; 2. Subjective Evaluation of Health Scale	The aim of the study was to explore the relationship between assessment of health and resiliency among mothers of children with ASD and TD children	BC <i>Coping Strategies</i> – Resiliency; xx <i>Family Adaptation</i> – Subjective Evaluation of Health
Lisak et al. (2017), Croatia	1 mother and one mother-father dyad of children with ASD	Not specified for the parents of children with ASD	3 years and 10 years	Qualitative interview	The purpose of this study was to explore parental experiences related to their child's educational system	bB <i>External Support</i> xx <i>Family Adeaptation</i> – Stress

(Continued)

Study, country of the study	Sample	Parent ages –Years (range and/or mean)	Child ages – Years (range and /or mean)	Instrument	Focus of the study	Double ABCX Model Factors
Milačić-Vidojević (2008), Serbia	105 parents of children with ASD (including some couples)	27–61 (M = 39.05)	3 years and 2 months–18 years and 4 months	1. Parenting Stress Index/Short Form	The study examines parent stress levels, and if there is any difference in stress in relation to gender and marital status, as well as child's characteristics.	aA Pile up – Financial Problems; bB External Support
Pejović-Milovančević et al. (2018), Serbia	231 parents of children with ASD (167 mothers and 64 fathers)	Not stated	M = 10.5	1. Affected Child Characteristics; 2. Service Encounters; 3. Parent/Caregiver Perceptions	The study explored parents' perception of support that they are receiving as well as their needs.	aA Pile up – Child's Problem; aA Pile up – Financial Stress; aA Pile up –Limits on Family Opportunity; aA Pile up – Personal Burden; aA Pile up – Excess Time Demand; cC Perception and Coherence –Pessimism; bB External support – Lack of Social Support; xX Family Adaptation – Poor Health/Mood; xX Family Adaptation – Lack of Family Integration
Pisula (2007), Poland	25 mothers of children with ASD and 25 mothers of children with DS	ASD 26–56 (M = 38); DS 30–58 (M = 40.44)	4–20	1. Questionnaire of Resources and Stress (QRS) for Families with Chronically Ill or Handicapped Members	The study explored if stress profiles are different between parents of children with ASD and DS.	cC Perception and Coherence – SOC; BC Coping Strategies
Pisula and Kossakowska (2010), Poland	26 couples of children with ASD and 29 of TD children	Mothers ASD 26–47 (M = 34); Fathers ASD 26–48 (M = 36); Mothers TD 26–48 (M = 32), Fathers TD 26–50 (M = 35)	ASD 3,7–5 (M = 5.12); TD 3–6.5 (M = 4.67)	1. Orientation to Life Questionnaire (SOC-29); 2. Ways of Coping Questionnaire (WCQ)	The purpose of this study was to explore the relationship between SOC and coping strategies, as well to see if the assessment of coping strategies and SOC are different between parents of children with ASD and parents of TD children	aA Pile up – Child's problem; bB Internal Resources –Family Functioning; xX Family Adaptation –Personal Problems; xX Family Adaptation – Family Problems xX Family Adaptation – Quality of Life
Pisula and Porębowicz-Dörsmann (2017), Poland	202 parents (49 mother–father dyads of children with ASD and 52 mother–father dyads of TD children)	Mothers ASD M = 39.56; Fathers ASD M = 41.87; Mothers TD M = 39.94; Fathers TD M = 42.63	ASD 5–17 (M = 10.24); TD 5–17 (M = 10.21)	1. Family Assessment Measure II; 2. Questionnaire of Resources and Stress for Families with Chronically Ill or Handicapped Members-Short form; 3. WHOQoL-BREF	The aim of this study was to explore family functioning among parents of children with ASD in Poland, as well as the relationship between family functioning, quality of life, and stress.	aA Pile up – ASD Symptoms Severity; xX Family Adaptation – Stress
Rudić et al. (2013), Serbia	167 parents of children with ASD	M = 37.35	Not stated	1. Parenting Stress Index; 2. Childhood Autism Rating Scale	The purpose of this study was to examine stress levels in parents of children with ASD. Also, the authors explored the correlation of stress in mothers with ASD symptom severity.	

(Continued)

Study, country of the study	Sample	Parent ages -Years (range and/or mean)	Child ages - Years (range and /or mean)	Instrument	Focus of the study	Double ABCX Model Factors
Schmidt et al. (2017), Slovenia	25 families with children with IDD and 19 families with children with ASD	Mothers M = 40.74; Fathers M = 43.62	IDD M = 14.86; ASD M = 11.63	1. Family Quality of Life Survey-2006 (FQOLS-2006) (measures 9 domains: Health, Financial Wellbeing, Family Relationships, Support from Others, Support from Services for People with Disability, Influence of Values, Careers, Leisure, Community Interaction)	The aim of this study was to examine quality of life among parents of children with ID and ASD and to compare their perceptions of family life domains.	bB External Support – Support from Others; bB External Support – Support from Services; bB Internal Resources – Family Relationships; xx Family Adaptation – Health; xx Family Adaptation–Financial Wellbeing; xx Family Adaptation –Careers xx Family Adaptation–Leisure; xx Family Adaptation–Community Participation; xx Family Adaptation – Quality of Life
Tiba et al. (2012), Romania	27 parents of children with ASD (22 mothers and five fathers)	29–53 (M = 37)	M = 10.3	1. Profile of Affective Distress Scale; 2. Automatic Thoughts Questionnaire; 3. Attitude Beliefs Scale - Short form; 4. Problem Behavior; 5. Positive Negative Emotions Parent Meta-Cognitive Beliefs Scale	The purpose of this study was to explore the relationship between cognitive vulnerability factors and the experience of stress and positive emotions in parents of children with ASD.	aA Pile up – Problem Behavior; cC Perception and Coherence – Automatic Positive and Negative Thoughts; cC Perception and Coherence – Irrational Beliefs; xx Family Adaptation – Stress
Troshanska et al. (2018), North Macedonia	70 caregivers of individuals with ASD	Not stated	Not stated	1. The Care-related Quality of Life instrument (CarerQoL)	The aim of this study was to explore caregivers' experiences of living with the individual with ASD and if their quality of life changed after attending parent education program ^a	aA Pile up – Financial Problems; bB External Support xx Family Adaptation – Quality of Life

Note. M – mean, SD – standard deviation, ASD – autism spectrum disorder, TD – typically developing, DS – Down syndrome, CP – cerebral palsy, IDD – intellectual or developmental disability. In order to be consistent, we used ASD across this review, although some studies applied the terms autism, pervasive developmental disorder or Asperger syndrome.

^aWe only report on Troshanska et al.'s pre-program data, as we excluded studies intervention data in our review.

reported that their child had more challenges in the physical domain, compared to mothers of children with DS; while Dabrowska and Pisula (2010) reported the opposite finding. In contrast, one study (Dabrowska and Pisula 2010) did not find that parents of children with ASD rated their child's physical abilities differently in comparison to parents of TD children. Additionally, parents of children with ASD reported greater personal burden and limited family opportunities compared to parents of TD children; however, the authors did not find differences related to financial stress (Dabrowska and Pisula 2010).

Three studies explored financial difficulties among families of children with ASD (Daniels *et al.* 2017, Pejović-Milovančević *et al.* 2018, Troshanska *et al.* 2018). The authors noted that in four countries (Croatia, Albania, Bulgaria, and Turkey), two-thirds of the caregivers disclosed that they experienced financial problems, and 50% of the participants had to stop working because of the child with ASD. In two studies, 70% and 53% of the parents reported financial problems, respectively (Pejović-Milovančević *et al.* 2018, Troshanska *et al.* 2018). Further, the study authors reported financial problems were significant predictors of lower satisfaction with external supports.

Two studies examined the relationship between child problem behaviors and symptom severity with cognitive vulnerability factors (Tiba *et al.* 2012) and stress (Rudić *et al.* 2013). Tiba *et al.* (2012) reported parents' negative emotions, negative automatic thoughts, and irrational beliefs were positively correlated with child problem behavior. On the other hand, problem behavior was not associated with metacognition about stress. Furthermore, one study did not identify a significant relationship between child ASD symptom severity and maternal stress (Rudić *et al.* 2013).

Adaptive resources (the **BB** factor)

Seven studies explored adaptive resources, including both external support and internal resources (Daniels *et al.* 2017, Lisak *et al.* 2017, Pejović-Milovančević *et al.* 2018, Pisula 2007, Pisula and Porębowicz-Dörsmann 2017, Schmidt *et al.* 2017, Troshanska *et al.* 2018). Below, we summarize results based on resource type.

External resources. Four studies examined parents' satisfaction with their external supports (Daniels *et al.* 2017, Lisak *et al.* 2017, Pejović-Milovančević *et al.* 2018, Troshanska *et al.* 2018). Over one-third (35%) of the caregivers reported that they had challenges accessing services for their children (Daniels *et al.* 2017). Greater satisfaction was linked with in-school tutors, training or assistance in managing child's needs, and a primary care doctor or pediatrician as an information source (Pejović-Milovančević *et al.* 2018). Parents' top

three areas where their child needed support were related to their child's education, getting welfare/social support and receiving adequate health care (Pejović-Milovančević *et al.* 2018). More specifically, parents reported a lack of information regarding child rights and school-based supports (Lisak *et al.* 2017). They also noted limited collaboration among experts, which led to multiple and repeated visits without receiving adequate information and support (Lisak *et al.* 2017). Parents also shared that they had to fight to enroll their children into mainstream preschools and to access other services (e.g. government funded personal assistant; Lisak *et al.* 2017)

The majority of parents reported receiving government support (61–72%; Daniels *et al.*, 2017; Pejović-Milovančević *et al.* 2018) and informal support (some support = 28.6%; a lot of support = 55.7%; Troshanska *et al.* 2018). Less than one-third of parents received support from advocacy groups/organizations or other assistance in managing child's need. Participants in both studies (Daniels *et al.*, 2017; Pejović-Milovančević *et al.* 2018) rated the Internet as a main information source, while the child's primary care doctor was rated the lowest.

Two studies explored differential experiences with external support based on child diagnosis. Overall, parents of children with ASD were less satisfied with their support than families of children with intellectual disabilities (Pisula 2007, Schmidt *et al.* 2017).

Internal resources. Two studies researched the families' internal resources, such as family relationships (Pisula and Porębowicz-Dörsmann 2017, Schmidt *et al.* 2017). Parents of children with ASD were less satisfied with family relationships compared to families with TD children (Pisula and Porębowicz-Dörsmann 2017) or families of children with intellectual disabilities (Schmidt *et al.* 2017). Furthermore, poor family functioning was correlated with higher stress and lower quality of life (Pisula and Porębowicz-Dörsmann 2017).

Perception and SOC (the **CC** factor)

Four studies explored parents' perceptions of stressful situations and SOC within families (Dabrowska 2008, Pisula and Kossakowska 2010, Pisula 2007, Tiba *et al.* 2012). Results related to SOC were mixed in the reviewed papers. Dabrowska (2008) revealed no SOC differences among fathers with children with ASD, DS, cerebral palsy (CP), and TD children, while Pisula and Kossakowska (2010) reported lower overall SOC in parents of children with ASD compared to parents of TD children. Further analysis revealed that parents of children with ASD expressed lower sense of meaningfulness and manageability compared to parents of TD children (Pisula and Kossakowska 2010). Although fathers of children with ASD in Dabrowska's study

(2008) did not rate their overall SOC differently compared to fathers of children with DS, they reported higher levels of sense of meaningfulness than fathers of children with DS. Moreover, Pisula (2007) examined pessimism among mothers of children with ASD and mothers of children with DS, finding no group differences.

One study examined perception and coherence within families of children with ASD and its relationship to different constructs. Tiba *et al.* (2012) reported that both irrational beliefs and automatic thoughts were positively related to negative affective distress; whereas irrational beliefs were negatively associated with positive emotions.

Coping (the BC factor)

Four studies explored coping in response to stressors, as well as its relationship with other psychological constructs (Dabrowska 2008, Dabrowska and Pisula 2010, Kasprzak *et al.* 2013, Pisula and Kossakowska 2010). Findings indicated that fathers of children with ASD applied more support-seeking strategies, compared to fathers of children with DS and CP (Dabrowska 2008). Compared to parents of TD children, Pisula and Kossakowska (2010) reported that parents of children with ASD applied escape-avoidance coping strategies more often. However, Dabrowska and Pisula (2010) found the opposite results: compared to TD children, parents of children with ASD used less social diversion (avoidance-oriented) strategies. Notably, researchers did not find differences related to the use of the majority of the coping strategies between parents of children with ASD and parents of children with DS, CP and TD children (Dabrowska 2008, Dabrowska and Pisula 2010, Pisula and Kossakowska 2010).

In addition, researchers explored relationships between coping strategies and SOC (Pisula and Kossakowska 2010), as well as stress (Dabrowska and Pisula 2010). Among families of children with ASD, SOC was positively correlated with self-controlling methods, seeking social support, and distancing strategies; and negatively correlated with accepting responsibility (Pisula and Kossakowska 2010). Furthermore, the authors reported that parents who used emotion-oriented coping styles reported higher stress levels (Dabrowska and Pisula 2010).

Adaptation (xX factor)

Eleven studies investigated different family adaptation outcomes. Five articles explored bonadaptation to stressors, such as improved quality of life and health (Benjak 2011, Kasprzak *et al.* 2013, Pisula and Porębowicz-Dörsmann 2017, Schmidt *et al.* 2017, Troshanska *et al.* 2018). Six studies examined parental stress as a maladaptation to stressors (Dabrowska and Pisula 2010, Milačić-Vidojević 2008, Pisula 2007,

Pisula and Porębowicz-Dörsmann 2017, Rudić *et al.* 2013, Tiba *et al.* 2012).

Bonadaptation

Parents of children with ASD in two studies evaluated their quality of life lower than parents of TD children (Benjak 2011, Pisula and Porębowicz-Dörsmann 2017); whereas another study found parents of children with intellectual disabilities reported better quality of life than parents of children with ASD (Schmidt *et al.* 2017). Furthermore, two studies reported that parents of children with ASD rated their health poorer than parents of TD children (Benjak 2011, Kasprzak *et al.* 2013), whereas only 20% and 31.4% caregivers did not report problems related to their mental and physical health, respectively (Troshanska *et al.* 2018). Moreover, Kasprzak *et al.* (2013) found a positive relationship between better health and optimism, as well as between health and use of adaptive coping strategies.

Maladaptation

Besides exploring overall stress within families, some studies also investigated other aspects of negative adaptation, such as family disharmony. Two studies found parents of children with ASD reported that their families experienced more disharmony and personal and family problems, compared to parents of TD children (Dabrowska and Pisula 2010, Pisula and Porębowicz-Dörsmann 2017). However, the researchers found no differences in maladaptive outcomes (e.g. family disharmony) between parents of children with ASD and DS (Dabrowska and Pisula 2010, Pisula 2007).

Three studies (Dabrowska and Pisula 2010, Milačić-Vidojević 2008, Pisula and Porębowicz-Dörsmann 2017) showed mixed results regarding differences between mothers' and fathers' reported stress. One study found that mothers of children with ASD had higher personal stress than fathers (Pisula and Porębowicz-Dörsmann 2017), while two studies did not find gender differences (Dabrowska and Pisula 2010, Milačić-Vidojević 2008). Furthermore, two studies examined parental stress level (Milačić-Vidojević 2008, Rudić *et al.* 2013). Participants in Rudić *et al.*'s study (2013) reported lower stress (41.3%) compared to the parents in Milačić-Vidojević's study (65.7%; 2008).

Discussion

The present review aimed to map the literature related to parents' experiences raising children with ASD in Eastern Europe. Clearly, this topic is overlooked in the literature, as we only identified 15 studies focusing on Eastern European populations. Furthermore, these studies were conducted in nine of the 17 Eastern European countries; further demonstration that the research base is underdeveloped. In addition, 14 out of 15 studies focused on children or young adults in transition period,

neglecting parents' experience of adults with ASD. We used the Double ABCX model (McCubbin and Patterson 1983) to organize our findings within a widely used theoretical framework. We found that parents of children with ASD overall reported more life-related challenges and greater maladaptation, compared to parents of TD children. These results are consistent with findings in the extant literature, which primarily focuses on Western Europe and North America (Abbeduto et al. 2004, Baker-Ericzen et al. 2005, Lecavalier et al. 2006, McStay et al. 2013). Below, we discuss our results from each ABCX Model factor, as well as how our findings from Eastern Europe align with literature outside of the region.

Pile-up stressors (aA factor)

Overall, child-related challenges were more present among families of children with ASD in comparison to children with DS and TD children, a common finding in the Western literature (e.g. see Griffith et al. 2010). Furthermore, multiple other studies outside of Eastern Europe have found a relationship between child behavior problems and parent stress (e.g. see Lecavalier et al. 2006, Paynter et al. 2013), a finding supported by one study in the current review (Tiba et al. 2012). However, contrary to the large body of the literature finding a positive relationship between child ASD symptom severity and parental stress (e.g. see Manning et al. 2011, Osborne et al. 2008), Rudić et al. (2013) found no such relationship among their sample of mothers. Notably, Paynter et al.' study (2013), which employed Double ABCX model for empirical testing of family adaption, also did not reveal such a relationship.

The studies in the present review reported mixed results of stress related to child physical difficulties between mother of children with ASD and DS (Dabrowska and Pisula 2010, Pisula 2007). There could be several possible reasons for this discrepancy. First, there could have been difference between the child samples, as there was no information about child physical and adaptive skills in either study. Secondly, studies explored reported physical skills using different subscales, which could reflect differences on the measurement level.

Parents of children with ASD also assessed their personal and family problems as more severe, compared to those with TD children. These results are in accordance with the previous findings from United States (U.S.; Lee et al. 2008) and United Kingdom (Fombonne et al. 2001). Nonetheless, with respect to financial problems, results from the present review were not unequivocal (Dabrowska and Pisula 2010, Daniels et al. 2017, Pejović-Milovančević et al. 2018, Troshanska et al. 2018). Consistent with Western research (Ouyang et al. 2014), three reviewed studies (Daniels et al. 2017, Pejović-Milovančević et al. 2018, Troshanska et al.

2018) revealed that the majority of parents experienced financial problems and subsequently stopped working. However, Dabrowska and Pisula (2010) found that families of children with ASD and TD children did not differ on financial stress. Given more than 60% of Dabrowska and Pisula's sample had university degrees and above-average monthly incomes in Poland (CEIC 2019), it is possible families had enough monetary resources for adequate child support.

Adaptive resources (the bB factor)

Despite the transitions and financial challenges which countries in Eastern Europe have experienced, we found only four studies exploring external resources available to parents. Families with children with ASD face various financial problems and service barriers (Daniels et al. 2017, Lisak et al. 2017, Pejović-Milovančević et al. 2018, Troshanska et al. 2018), yet this review highlighted little is known about these challenges in the Eastern European context.

While many of the parents reported receiving governmental support (Daniels et al. 2017, Pejović-Milovančević et al. 2018), a third of Daniels et al.'s (2017) sample reported challenges with service access, including educational support, financial resources, and healthcare. Therefore, despite financial aid that families obtained, they seemed insufficient to cover needed services. Clearly, more work is needed to further understand financial issues facing Eastern European families of individuals with ASD.

Using the Double ABCX model, Manning et al. (2011) found that family functioning among families with ASD was explained by child behavior severity, coping by relying on others and subjective social status. The complexity of family functioning as a resource for family adaptation to stressful situations can explain why these families rated their family relationships lower than families of TD children and children with ID (Pisula and Porębowicz-Dörsmann 2017, Schmidt et al. 2017). Furthermore, previous research showed negative relationships between satisfaction with family relationship and external support (Paynter et al. 2013), which could also explain why studies reviewed in this paper reported lower family functioning among families of children with ASD.

Perception and sense of coherence (the cC factor)

Eastern European researchers explored family perception of stressors, and parents' methods to reframe and give meaning to new situations. Tiba et al. (2012) found negative thoughts were positively associated with parental distress, while positive emotions were negatively correlated with stress. These findings were supported by extant research, as Hassall and Rose (2005) emphasized the importance of parental cognitions in

adjustment and managing child- and life-related challenges.

Findings from the current review regarding SOC were mixed, consistent with the previous research. For example, one non-Eastern European study found parents of children of ASD have lower SOC in comparison with parents of TD children (Sivberg 2002a), whereas Olsson and Hwang (2002) found only mothers – but not fathers – had comparatively lower SOC. Furthermore, Pisula (2007) found mothers of children with ASD and DS did not report different pessimism levels, a finding inconsistent with U.S. research (Abbeduto *et al.* 2004). More research is needed to explore potential differences based on gender and diagnosis.

Coping (the BC factor)

Several of the reviewed studies explored potential differences in parental coping strategies by child diagnosis, a hypothesis supported by extant research (e.g. see Hastings *et al.* 2005). Yet, despite the results from this review that the majority of parental coping strategies did not differ between diagnostic groups, some differences still emerged. For example, fathers of children with ASD engaged more in support-seeking strategies in comparison to fathers of children with DS and CP (Dabrowska 2008), a finding inconsistent with previous research not finding such differences (e.g. see Hartley *et al.* 2012). Furthermore, while Pisula and Kossakowska (2010) reported that parents of children with ASD used more escape-avoidance strategies, in line with previous studies from Western Europe (Cuzzocrea *et al.* 2015, Sivberg 2002b), Dabrowska and Pisula (2010) reported families of preschoolers with ASD engaged in fewer avoidance strategies than families of TD children. Differences in these findings could be related to samples, as the two Eastern European studies differed on educational level, employment, and child service use. Moreover, Dabrowska and Pisula (2010) did not confirm previous findings related to a positive association between avoidance coping strategies and parental stress (Hastings *et al.* 2005, Paynter *et al.* 2013). In the Eastern European sample, more educated parents and those using emotion-oriented coping styles reported higher stress levels. Further research could shed light on the contributing factors for developing different coping style in parents inhabiting this part of Europe.

Adaptation (xX factor)

The Double ABCX Model is ultimately focused on family adaptation. Previous research found family quality of life was positively influenced by social support and parents' SOC and negatively by ASD symptom severity (Pozo *et al.* 2014). The present review found parents of children with ASD reported poorer quality of

life and health than parents of TD children and children with ID, consistent with Western research (e.g. Lee *et al.* 2009). Similarly, this review found families of children with ASD reported greater stress level than parents of TD children, likewise consistent with previous studies (e.g. Abbeduto *et al.* 2004, Brobst *et al.* 2009). Similar to research in Canada (Perry *et al.* 2004), the present review found no differences on family disharmony between parents of children with ASD and DS (Dabrowska and Pisula 2010, Pisula 2007). Finally, the findings related to gender differences in parenting stress were inconsistent in this review, as they were in previous studies (e.g. see Gray and Holden 1992, Hastings 2003).

Limitations

Several limitations should be taken in consideration when interpreting our results. First, we included only peer-reviewed articles available in English, Serbian, and Croatian, potentially missing papers written in other languages or formats (e.g. dissertations). In addition, only the first author reviewed Serbian and Croatian papers. Finally, despite a comprehensive literature search, it is possible that some articles were not screened and thus excluded from our review.

Conclusion

Parents of children with ASD in Eastern Europe reported more life-related challenges and greater maladaptation compared to parents of TD children, reflecting findings in the Western literature. These findings suggest that regardless of geographical and cultural characteristics, certain similarities in the stress profiles of families of children with ASD remain evident. However, we observed the greatest discrepancies compared to international findings were in parental coping strategies. Thus, future research in Eastern Europe should seek to clarify the relationship between coping styles and parental stress, along with identifying commonly used parental coping styles.

The small number of the included papers (15) from nine countries suggests that parental experiences of children with ASD in Eastern Europe are underexplored. Therefore, research should aim to bridge this gap and explore not only adaption (such as stress and quality of life) among families of children with ASD, but also internal and external family resources, effects of child problem behavior on parents, and families' perceptions of stressors. Future research could consider applying the Double ABCX model to frame results, in order to conceptualize family adaptation processes into a theoretical framework.

Conflict of interest

No potential conflict of interest was reported by the authors.

Funding

No external funding was received for the research reported in the paper.

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