

PARENTAL PERSPECTIVES ON SUPPORT NEEDS AND AVAILABILITY OF AUTISM SERVICES IN SOUTH AND SOUTH-EASTERN EUROPE

Author Accepted Manuscript

Advances in Autism, Emerald Publishing, accepted for publication 12-May-2021

Ivana VASILEVSKA PETROVSKA¹, Anastasia C. GIANNAKOPOULOU², Vassiliki TSECOURA², Angela WINSTANLEY³, Roberto MILETTO⁴, Georgeta CONSTANȚA ROȘCA⁵, Biserka IVANOVA⁶, Vasiliki KAISA⁷, and Vladimir TRAJKOVSKI^{1,8}

1 Macedonian Scientific Society for autism, Skopje, Macedonia

2 Cyclisis, Patras, Greece

3 Shipcon Ltd, Limassol, Cyprus

4 Maendeleo for Children, Rome, Italy

5 Smaranda Gheorghiu School, Târgoviște, Romania

6 The First National Dyslexia Centre, Rousse, Bulgaria

7 Association of People with Pervasive Developmental Disorder, Autism and Asperger, Komotini, Greece

8 Institute of Special Education and Rehabilitation, Faculty of Philosophy, University "Ss. Cyril and Methodius", Skopje, Macedonia

Abstract

Purpose

Amid the expanding demand on the autism service delivery system, little knowledge is accumulated regarding access and availability of support and services in the region of Southern and South-Eastern Europe - critical for improvement of individual outcomes, as well as family quality of life. The purpose of this paper is to explore how service delivery systems are responding to the specific needs of autistic individuals, as perceived by parents.

Design

A qualitative exploratory descriptive method was employed. Thematic analysis was used as a pragmatic method to report on the experiences of parents (92% mothers, n = 55) of children, youth and young autistic adults (76% male) across six South and South-Eastern European counties that participated in a survey involving a combination of qualitative and quantitative data collection.

Findings

Thematic analysis revealed three broad themes: 1) challenging pathways to service utilization, 2) insufficient service options and providers' competences and 3) lack of continuous and meaningful support across life span.

Originality/Value

The findings from this study add to the small body of literature specific to South and South-Eastern Europe, by exposing problems related to meeting the needs of autistic children and youth and potential ways to strengthen services, as perceived by parents. The findings have potential policy ramifications for the region in which the research was conducted.

Key words: Autism, support, services, parents' survey, South and South-East Europe

Introduction

Autism Spectrum Disorders/Conditions are complex neurodevelopmental conditions characterized by atypical social communication and restricted and repetitive patterns of behavior and interests, including atypical reactions to sensory stimuli. Access to timely, appropriate and quality support, including in-school, community and health services is critical, in terms of significant improvement of individual outcomes (Schreibman et al., 2015; Zwaigenbaum et al., 2015), family quality of life (Jones, Bremer, & Lloyd, 2017) and reducing lifetime costs (Jarbrink, 2007).

In spite of the expanding demand on the service delivery system, services for autistic individuals have been frequently described as limited, unavailable, inaccessible, inappropriate and costly. Literature examining availability and accessibility of services shows that this group faces limitations and barriers to accessing the service they need across the life span (Anderson, Lupfer, & Shattuck, 2018; Baio et al., 2018; Chiri & Warfield, 2012; Cidav, Lawer, Marcus, & Mandell, 2013; Hodgetts, Zwaigenbaum, & Nicholas, 2015; Oswald, Haworth, Mackenzie, & Willis, 2017; Rogers, Goddard, Hill, Henry, & Crane, 2016)

DePappe and Lindsay systematically synthesized studies' findings across various countries including United States, Australia, Canada, England, India, Taiwan, Turkey, Belgium, China, Israel, Saudi Arabia and Wales. They looked at 6 main areas of parental experiences: pre-diagnosis, diagnosis, family life adjustment, navigating the system, parental empowerment, and moving forward; reportedly, challenges and negative implications for parents in obtaining services and support were present in all these stages, in various degrees across countries (2015). It is observed that the varying experiences of families have been associated with factors linked, not only to the child's characteristics, but also to family characteristics, socio-demographic, cultural and the characteristics of service delivery (Bejarano-Martín et al., 2020; Salomone et al., 2016). For illustration, decades of research demonstrate that children from racially and ethnically diverse groups, families with limited language proficiency, families from low-income households, and families located in rural or remote areas are diagnosed much later than children of higher socioeconomic status. (Locke et al., 2017; McLennan, Huculak, & Sheehan, 2008; Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007; Zeleke, Hughes, & Drozda, 2019). Additionally, research shows that low-and middle-income countries have struggled to build the resources and systems to respond to the needs of a growing number of autistic individuals (Dababnah, 2018).

In Europe, very few studies provide comprehensive description of support needs and availability of services for children, and particularly autistic youth and adults. The COST-ESSEA study (Salomone, et al., 2016) conducted across 18 countries documented the service use experience among 1700 parents of children aged seven years or younger. Although the study did not focus on low-and middle-income countries in Europe, it included, among others, Romania, Italy, Cyprus and North Macedonia. Almost 1 in 10 parents who took part in the survey reported that their child was not currently receiving any type of intervention. However, differential patterns of therapy utilization were observed in the West, North, East and South areas of Europe, geographical regions also characterized by similar economic and cultural background within regions. Another recent study by Bejarano-Martín et. al. looked at services for children under 6 years of age in 14 European countries. Satisfaction with services measured using an ordinal scale from 1 to 7, with 2032 respondents, was lower in the parents' group (mean = 4.6) compared to practitioners (mean = 4.9) (2020). Parents' dissatisfaction with provided information, received support and access delays observed in this study is consistent with previous findings (Dymond, et al., 2007; Hodgetts, et al., 2015; Liptak, Stuart, & Auinger, 2006; Rogers, et al., 2016)

Both European studies (Bejarano-Martín, et al., 2020; Salomone, et al., 2016) explore types of services used and parental satisfaction with services, however do not attempt to examine possible accessibility, availability or knowledge barriers that could influence service utilization, and explain variability in parental experiences. In addition, very little is known about service needs and barriers to services among older children, youth and adults in Europe. To this end, we utilized the Autism_PCP (2019-2021) network and applied an exploratory approach, to build on the limited existent understanding of the experiences of families of autistic children and youth, particularly for the countries Bulgaria, Cyprus, Greece, Italy, North Macedonia and Romania, regarding access and availability of support including in-school and out of school services and treatment. This group of countries located the region of Southern and South-Eastern Europe consists of middle-and high-income countries, where in spite of country differences, common regional experiences and needs are observed. In a previous study conducted by the Autism_PCP network, examining stakeholders' perspectives on environmental barriers and facilitators to participation of autistic people in the mentioned South and South-Eastern European countries, we observed a perceived lack of specific understanding and approaches in meeting the needs of this population. Several perceived barriers to participation of persons with autism were identified by parents and autistic individuals. Attitudinal

barriers that stem from inaccurate beliefs and a lack of direct knowledge impacted accessibility on all levels. Communication barriers and systemic barriers, rooted in attitudes, also affected the social participation of individuals with autism (Vasilevska Petrovska et al., 2019).

In addition to lack of primary data on autism, caregivers of autistic children in South and South-East Europe experience considerable stigma, challenges in access to care and services, as well as financial strains related to service utilization. However, additional qualitative research is required to capture the breadth and depth of the problem more elaborately (Daniels et al., 2017). Fragmentary findings from the aforementioned countries are introduced below.

Parents in Bulgaria have recently reported delays accessing service in the year preceding the time of the study due to: ineligibility (29%), unavailability of services (38%), waiting list placements (16%), financial strains (30%), lack of information (31) (Daniels, et al., 2017). In the Salomone, et.al study, nearly 10% of children in Bulgaria were not receiving any intervention at the time of study. The same tendency was observed in Romania and Italy, while in North Macedonia this experience was reported more often (between 10% and 20 %) (2016). In North Macedonia, an economically developing country, autistic persons are faced with limited professional and financial resources to access adequate educational, health and social services. Families experience challenges both on a cultural and a practical level that they are unequipped to handle with the tools and support systems available to them (Hansen et al., 2017). Similarly, in Greece, recent parents' survey observed perceived insufficient resources and training, and lack of scientifically based practice approaches, leaving many parents dissatisfied with the services provided and exposed to tremendous stress. In addition, many Greek parents experienced negative stereotyping and prejudice. (Veroni, 2019). The small population of Cyprus is also facing challenges linked to availability of resources, appropriate placement and individualized interventions. Lack of formal support and experiences of stigma, were also reported by mothers of children with disabilities in Cyprus society (Stylianou, 2017). As in all previously mentioned countries, lack of primary data on autism renders the condition invisible in Romania. Parents of children with autism in Romania face stress, depression, social stigma, very little systemic support, and limited service availability (Grasu, 2018). In Italy, there is a necessity of strengthening services' structural capacity in order to meet adequately the requirements of persons with autism, while lacking an Italian national estimate of autism prevalence. Considerable variability is observed across geographical macro-areas in the provision of diagnostic and intervention services. In particular, in the

South and partially in the Islands the service capacity is lower than in the North with respect to day-care and long-care facilities, availability of professionals, and provision of intervention services (Borgi, Ambrosio, Cordella, Chiarotti, & Venerosi, 2019).

Aims

To explore their perceptions about how service delivery systems are responding to the specific needs of autistic individuals we used a survey with broad open - ended research questions. The chosen qualitative approach is considered particularly suited to provide readily understood information to participants and non-researchers, making the results interpretable by the general community, program managers, other stakeholders, and to increase visibility of the voices and experiences of marginalized groups (Khanlou et al., 2017). Several main recommendations for future research, policy and practice are discussed in order to provide an evidence-based framework for practitioners, decision-makers and researchers in the region to consider, enabling them to incorporate the views of these groups into their efforts to optimize autism services.

Method

Participants

Participants were recruited from six South-Eastern European countries Bulgaria (n=7), Cyprus (n=8), Greece (n=10), Italy (n=8), Macedonia (n=15), Romania (n=7). The sampling frame was purposive using recruitment tools such as flyers, emails and word of mouth sent to diverse service organizations, including schools, public and private centers and organizations that support autistic children and youth and their families. Snowball sampling was also used in order to reach a broader base of relevant stakeholders. No incentives were provided for participating. Total of 55 parents (92% mothers) of autistic children, youth and young adults (76% male) consented to participate in the study. Parents' average age at the time of the questionnaire was 37.8 years (SD = 6.7). Parents reported their children's diagnoses, given by a relevant clinician; we did not independently verify the diagnoses. Children's average age at the time of the survey was 13.9 years (SD = 8.07); most were between 3 and 17 years of age (75%), with a range from 3 years to 35 years. Demographic characteristics of participants are shown in Table 1.

Table I. Demographic Characteristics of Participants (N = 55)

Characteristic	Frequency (%)
Highest level of education completed	
High school	3 (5.5)
Bachelor's degree	41 (74.5)
Post-Bachelor's degree	11 (20.0)
Socio-economic status	
Low	6 (10.9)
Lower middle	40 (72.7)
Upper middle	9 (16.4)
Area of living	
An urban area	31 (56.4)
Semi urban area	6 (10.9)
Rural area (remote areas included)	18 (32.7)
Marital status	
Married	42 (76.4)
Divorced	8 (14.5)
Separated, single, or widowed	5 (9.1)

Instrument

The survey was designed to map the perceived cross-country barriers and facilitators to participation for autistic children and youth. It was developed by the AUTISM_PCP network, comprised of partnership with parents, professionals and academics from South- Eastern Europe. An initial survey was produced following an extensive literature research. To facilitate further understanding of the daily challenges experienced by persons on the spectrum and their families the broad open – ended questionnaire format addressed several topics including: anxiety (stress, sense of fear); difficulties in social interaction; isolation/loneliness; sensory issues; poor emotional expression; conflicts and aggression; task avoidance/boredom; repetitiveness and perseverance; memory issues; difficulties with time management; pica, and “other issues”. Each topic was discussed in the frame of four questions or sub-topics: (1) is there any intervention/support in place right now (if needed)? (2) What is working? (3) What is not working? (4) What would be required to help? A sample question is “In regard to the sensory issues, what kind of service/support are you getting at the moment? What are the positive aspects of the support you are getting? What are the negative aspects of the support you are receiving? What is necessary to improve your experience with the services/support you need?”.

The initial survey was piloted in three counties (Greece, North Macedonia and Cyprus), and the final survey included adaptations to questions' content, format and accessibility based on the feedback from the piloting phase. Participants in the piloting phase also participated in the final survey. All participants were advised to discuss/ answer only topics relevant to them and the child/youth. In this paper, we focus on the findings related to experiences with availability and accessibility of services and appropriateness of support.

Data analysis

Thematic analysis of the questionnaire data was undertaken. Semantic and latent analysis was done inductively and involved generation of initial codes followed by collation of information coded with the same code, and sorting different codes into preliminary categories and themes based on similarity in concepts. The lead researcher undertook the reflective thematic analysis, then the research team came together to discuss and refine constructed themes until final conceptualization were achieved (Braun & Clarke, 2006).

Results

In relation to the support needs of autistic family members parents reported areas of need that are common challenges for autistic individuals, well documented in the literature. Parents reported the highest frequency of support need related to anxiety (96.4%), and the least frequent support need related to challenging behavior (self-injurious behavior including biting, pinching, kicking or pica) (52.7%). Of those who reported they would like their child to receive certain type of support and answered the question on types of support needed and received, the average frequency on needed but unreceived support was disturbing 49.9 %. Although significantly variable, parents report high unmet needs profile with frequency of unmet support needs ranging from 35.8% for anxiety to 75.9% for self-injurious challenging behavior. Other most prevalent areas where support is unavailable include social and communication skills (66.7%), sensory issues (64.7%), isolation, loneliness and depression (56.8%) and restricted and repetitive behaviors (53.8%) (Table 2).

Table II. Frequency of various support needs in the sample (n = 55) and comparison of support received or currently receiving to support participants needed but had not received

Area of support need	Experiencing support need (%)	Receiving intervention/ Support (%)	Not receiving intervention/ support (%)
Anxiety	53 (96.4)	34 (64.2)	19 (35.8)
Emotional regulation	40 (72.7)	21 (52.5)	19 (47.5)
Conflicts, aggression towards others	30 (54.6)	17 (56.7)	13 (43.3)
Self-injurious challenging behaviour ¹	29 (52.7)	7 (24.1)	22 (75.9)
Social and communication skills	39 (70.9)	13 (33.3)	26 (66.7)
Isolation/loneliness/depression	37 (67.3)	16 (43.2)	21 (56.8)
Sensory issues	34 (61.8)	12 (35.3)	22 (64.7)
Restricted and repetitive behaviour	39 (70.9)	18 (46.2)	21 (53.8)
Memory issues	35 (63.6)	20 (57.1)	15 (42.8)
Time management and organization	32 (58.2)	18 (56.3)	14 (43.7)
Task avoidance/Boredom	43 (78.2)	27 (62.7)	16 (37.2)

The unmet support needs are elaborated more thoroughly in the three broad themes that emerged from the data. The first theme refers to challenges in accessing support and services; the second reflects the need for wider range of service options offered by support systems; the third emphasizes individualization and flexibility in support over the life course of autistic individuals. Within the results below, themes are identified as subheadings. Data extracts have been translated and edited minimally to aid readability and comprehension.

Challenging pathways to service utilization

Parents often talked about difficulties obtaining practical information on practices and methods that best suit their child's needs, and in what way these practices may promote individual growth. They felt strongly about lack of transparency about the available options and described the time-consuming process of locating different options as a "full-time job". "When we were given the diagnosis, it was so

¹ (biting, pinching, kicking or pica)

important to hear about treatment options. Simply giving a diagnosis is not adequate; we needed to hear what choices we have to go about it”.

Many parents who managed to locate appropriate services faced issues concerning eligibility, long waiting lists and short hours of government funded services such as respite, in- home and residential services, speech and language therapy, sensory integration and occupational therapy, ABA and other comprehensive intervention programs. High functioning individuals with higher IQs rarely qualified for services despite the significant challenges they faced. The frustration about eligibility is illustrated by one parent whose daughter was not intellectually disabled: “She is not eligible for existing programs. This is an awful thing, you know she is not learning disabled, she is not mentally ill, she is not physically disabled. Ironically, being high functional may be her handicap. Her form of autism is invisible in this country. So, who would I go to?” In many parents’ views, eliminating waiting lists is required, because children “just don’t have the time to wait”. For example, one parent stated, “we waited 3 years for Occupational therapy. We applied right after diagnosis; it was only recently that we got the letter, just recently. We wasted 3 valuable years from our lives.”

Some parents with negative experiences in mainstream schools sought a place for their child in an autism specific school environment i.e. special school or special classes integrated in mainstream schools. They describe the “struggle” to locate appropriate school placement as “trying to convince professionals who make the placement decision what the real problems actually are, trying to get your child in an autism school”.

Another significant concern was the financial burden accessing services that were only commercially available. Increased government funding for needed services is required as paying out of pocket for treatment and services produced a financial strain on the family and presented a common barrier to service access. For some parents this was a cost that must be covered because of the benefits for the child. One parent illustrated it in the following way “nothing else worked. Some source of distress cannot be realistically avoided, and we were told there are behavioral techniques to allow a child to gradually accept the unpleasant sensory sensation. Cognitive behavioral therapy was really helping him gradually increase tolerance to overwhelming sensory experiences. At the same time, it meant more mounting debt for us. Looking back, I really don’t know how we ever managed. We believed with all of our heart that it would eventually pay off. The financial sacrifices we made were worth every penny.”

Financial barriers seem more pronounced for families of children with complex needs that require greater number of different services, as well as for low-income families. Further, many participants who described complex needs necessitating a range of services across sectors, stressed that, coordination of services was often lacking. “It’s very helpful to have one person that connects all different services”- one parent shared a positive experience with an organization that provided help for parents to navigate the system and different service sectors, however this was project-based and discontinued.

Insufficient service options and providers’ competence

This theme reflects the general impressions of lack of service options to meet diverse needs more considerably. Children often needed services that were unavailable. The desired unavailable services included applied behavioral analysis and behavior support planning, social skills training/social activities, sensory integration therapy and sensory adaptations planning. Table 4 describes the frequency and percentage of needed but unavailable services.

Table III. Frequency of needed but unavailable services (n = 55)

Type of service	Frequency (%)
Applied behavioural analysis	29 (52.7)
Social skills training/	27 (49.1)
Behaviour support planning	25 (45.5)
Alternative and augmentative communication training	21 (38.2)
Social activities	19 (34.5)
Sensory integration therapy	18 (32.7)
Sensory adaptations in educational planning,	16 (29.1)
Respite care	15 (27.3)
Vocational training	15 (27.3)
Assistive technology	12 (21.8)
Transition/adult services	9 (16.4)
Services for high functioning children	8 (14.5)
Home based services	7 (12.7)
Occupational therapy	6 (10.9)
Music therapy	5 (9.1)

Desired services to some extent directly relate to the most frequently reported unmet support needs for self-injurious challenging behavior (biting, pinching, kicking or pica), followed by loneliness and depression, and restricted and repetitive behavior (Table 2). However, the desired service options reflect the range of evidence-based approaches and treatments, as there is an array of programs, approaches, and services to meet a certain need. This suggests that more diversity in community and in-school service options is needed to meet these needs. Respite service was mentioned frequently across different topics as a required and desirable support for the families.

A group of parents felt that the support available in inclusive school environments is not sufficiently specialized for the needs of autistic children. Some of them pointed out that the inclusive schools are understaffed resulting in very high teacher- student ratios, and lack of teaching assistants. Hence, many parents advocated for more specialized one -on one support, and more school-based intervention programs and accommodations regarding challenging behavior, sensory issues, loneliness, isolation and depression and social skills.

In addition, some parents reported lack of appropriate intervention programs for specific challenges of autistic children and youth in specialized settings as well. For illustration, one parent stated, “My child has been having severe behavior problems for long time and still doesn’t get the support he needs. There is no behavior specialist in our community, the [special] school doesn’t know how to deal with his behavior and I’m constantly called in to take him home. Their approach is only to advocate for pharmacological treatment. This is a nightmare for teachers as well as parents” reflecting a systemic barrier experienced by many parents in the sample. There was a noted tendency regarding individuals with challenging behaviors who are mostly served by the special school system, and currently do not get the support they need to be educated, to be channeled into disability day care centers, and not given other opportunities.

Many schools do not provide support for language and communication challenges faced by some autistic children. Due to lack of functional speech or assisted communication, children often develop inappropriate or challenging behaviors as means of communication. One parent noted, “When he is not well, he can’t communicate his pain, so he is acting out, then this is perceived as bad behavior”. Although, some children have access to speech and language therapy in special schools, parents feel that there should be an adequate framework within the education system to support other forms of assisted and augmentative communication to overcome communication barriers faced by children.

“My child is 15, and cannot speak. My wife and I are his voice. Many children on the spectrum can’t speak for themselves. Without communication, how can children learn, be part of the community and have a good life?”

A majority of parents expressed the need for professionals who work with autistic children and youth, to be more qualified and experienced in the area of autism. Parents feel that “many professionals should be given proper training” considering in school and community services as well. Many participants expressed concerns about lack of awareness regarding the needs of children and misconceptions about autism in schools. This was generally mentioned in relation to lack of positive behavioral support and sensory adaptations in the school environment. Reflecting on how his child’s repetitive behavior was managed in school one parents stated “...the biggest mistake that they [teachers] make is to assume that they must try to stop the action. Interrupting the behavior with shouting/ talk in a loud voice is not the effective way. Everyone [in the school] should have the same positive approach and think what the he [the child] can do instead”.

Regarding community services, numerous negative experiences were indicative of professionals’ poor understanding of autism. In one parent’s words “many professionals needed to “catch up”, a lot of them are years behind”. Generally, shortage in autism specialization i.e. “knowledgeable and sensitive providers” was present across service providers, and better educational and pre-service training programs were advocated.

Lack of continuous and meaningful support across life span

A need for consistency as well as flexibility in support over the life course was identified. Continuous support across all ages, as well as services tailored to individual and family needs are two aspects of this broad theme. Some parents expressed their frustrations that therapeutic community services available for preschool aged children could not be accessed in schools. They felt that continuity was an important factor for effectiveness of the services - “They [early intervention service and school] should all plan together so they are all working in the same outcome”. We hear a lot about the ways in which health and education should be working together but it just really isn’t happening and I can’t understand why the investment put into my child at this early stage isn’t continued in schools.” In schools, consistency and continuity of support was overshadowed by high staff turnover. Parents expressed concerns that personal or educational assistants were “changing very often”, resulting in poor continuity and consistency of support.

Numerous respondents in our study discussed the gap in services for older children and youth. They shared the perception that resources were becoming scarcer as their child got older, as new challenges are emerging for many children, particularly in puberty or transition to adulthood. Additionally, they shared “stressful and overwhelming” experiences for the child/person and whole family when transitioning to school and out of school. Consistency and continuity of support over time and in line with the changing needs of the service users can greatly improve the experiences of transitions aged individuals, and will ensure better outcomes. Transition/adult services and support are required to plan for employment, housing, and independence. “Autism doesn’t go away after school you know. We were going blind every step of the way, to figure out how to come up with the support for our child, because you just don’t know, and they [autistic youth] deserve the same quality of life as any other person and they don’t get it”.

Majority of parents in this group shared their greatest concern about what will happen with their adult children when they will not be able to take care of them. “He copes on a day to day level, but still very vulnerable and still needs support to certain extent. The idea of sticking your kid in a group home is really frightening, without good programs, we are lost.” Of the parents whose children were aged 16 and over, all felt that the lack of employment support was an important barrier to independence. They all agreed that there “needs to be a way to support autistic individuals into employment and find the right positions for them, and employers to become more aware and more autism friendly”. Many autistic adults attend day care centers, as they are unable to participate in employment or further education. The general experience was that these services are typically under resourced and rarely provide meaningful programs involving social development, education and work. One parent described this service as “little more than “childminding” for adults.

Out of the respondents who experienced the lack of appropriate and meaningful support for the diverse needs of their child, vast majority highlighted a need for individually tailored supports in community and school services as opposed to “imposing a particular regime”. Even when able to successfully access a service, they felt that the service did not suit their needs. Parents recognize that autistic children have unique and heterogeneous profiles of strengths and weaknesses. An effective support must take in to account the individual’s characteristics as well as and the family in order to define goals and strategies by which the goals can be achieved. For illustration, “Finding a place [service] was very exhausting when you have a child with complex and serious special needs who is

also extremely able in specific areas. He doesn't fit conventional concepts of 'disabled' child nor 'normal' child. Schools need to be more flexible in ensuring best services are provided for every child." The lack of individualized support was also evident in mental health service where "professionals were unable or unwilling" to shift their intervention approaches to meet the needs of a young autistic woman.

Individualization was particularly important for parents of transition-aged children who were or are yet to face new challenges. In addition to individualized programs, they advocated for more person-centered practices (PCP) for mitigating transition problems and ensuring good quality of life. Although there are important differences in typical strengths and limitations between people with ASC and those with LD for example, often, autistic children are expected to use LD specific approaches and models such as PCP. Without autism specific and individual accommodations and adaptations "it can be very difficult and ineffective to plan for a person with an ASC". In the absence of individualized support, many families feel "abandoned and alone", leading to carer stress and depression.

Parents feel that they and autism persons themselves should be more involved in the decision-making process, and to be given opportunities and information to make decisions and plan more meaningful services and treatment. Most parents described the relationship with professionals as hierarchical and paternalistic as opposed to an equal partnership. Parents often reported feeling not listened to, not acknowledged and only expected to implement what they have been told, by the more knowledgeable. The following statement is representative of many parents' opinions: "one of the major frustrations we have faced is in having our expert knowledge of our child ignored or undermined by those who are, in theory, our 'equal partners'." Parents frequently talked about not having the chance to say what is important to them, what are their priorities and values; not being provided enough time to discuss things with providers and seldom have they had opportunity to discuss their feelings. "You know the doctors don't seem to take that on board, how the parent could be feeling. You know, it seems to always be about the child and of course, you know, the child is important but the parent is as well, because they are the one that has got to look after the child". "it would be nice if professionals would listen a bit more because the very least, they can do is actually take real notice of the people they are working with and if a parent says I think this is a problem to really listen to it". A portion of opinions suggested that the education system should involve parents more to support their

children's learning – “to work with us and share ideas” in the educational planning. “We as parents always have a greater, a more than equal, interest in their children's well-being than anyone else”.

Discussion

The purpose of this study was to explore the experiences of parents of autistic children and youth in relation to support and services in Southern and South-Eastern Europe. The results suggest that autistic children and youth in South-Eastern Europe are a highly underserved population. A concerning portion of close to 50% of perceived needs of children and youth are currently not being met. The analysis rendered three broad themes that describe the barriers resulting in high unmet needs profile among this population. First, challenging pathways to service utilization that include problems with accessibility of existing services and support reported by parents, related to time and effort required to advocate for and obtain support as well as information about available options is consistent with previously documented findings (Daniels, et al., 2017). The competing public health priorities in low and middle-income countries contribute to the lack of funding for autism services and support. The significant financial burden on families associated with supporting an autistic individual has been well documented (Daniels, et al., 2017; Dymond, et al., 2007; Platos & Pisula, 2019). Increased funding allocated in the form of reimbursement of commercially available services can lift the financial barrier identified in accessing autism services.

Next, our results show a limited range of available services that is not sufficient to meet the support needs of individuals on the spectrum. The most critical areas of needs include management of challenging behaviors, social and communication skills, atypical sensory reactivity, and loneliness and depression. Autistic individuals have diverse support needs and the support systems are lacking specific understanding in meeting those needs.

When autistic children enter the school system, educational support becomes a major source of focused/targeted interventions for children with ASC (Lai, et al., 2020). More therapeutic interventions should be available to all autistic children in the school system. Appropriate individualized programs are needed to address the diverse and multiple areas of need, beyond academic and daily living skills. The behavioral challenges of autistic students are often misunderstood and mismanaged. Along with social and communication skills, behavior management needs to be included in programs and services, for all students that need that type of support.

Social and communication skills were the second most frequent area of unavailable support. This area is affected in various extents in individuals with autism across the spectrum and life span. As a person's human right, communication in any form should be supported and augmented. Moreover, without adequate external communication support many individuals are unlikely to engage in successful interactions, social participation, or learning (Ghanouni et al., 2019). Individuals facing communication barriers often develop behaviors that get them "labelled" as being difficult and/or dangerous (Kevan, 2003). This may further limit their access to services. Hence, there needs to be an adequate framework across early education, in-school, community and health services to support language and other forms of assisted communication of individuals with autism of all ages that have a co-occurring language and communication condition. A concerning finding is the lack of autism-specific competences among service providers. Recently, culturally diverse caregivers of autistic children have reported that lack of provider knowledge of the condition resulted in misdiagnosis and delayed access to services (Stahmer et al., 2019). This has also been confirmed by various service providers including mental health professionals (Zerbo, Massolo, Qian, & Croen, 2015), special education teachers (Hendricks, 2011), speech language pathologists (Schwartz & Drager, 2008). These professionals reported lack of training and skills for working with autistic population. Similarly, a study of pre-service early education, primary education and special education teachers' knowledge about autism has been conducted. The findings show that although all students increased their knowledge through years 1 to 4 of training, early and primary education teachers showed the smallest gains in autism knowledge (Sanz Cervera, Fernandez, Pastor, & Tarraga-Minguez, 2017). Further research is warranted to determine how autism knowledge in service providers relates to clients' outcomes, or the quality of service provision. This can be facilitated by a reliable and valid measure of autism knowledge designed for professional populations (McClain, Harris, Haverkamp, Golson, & Schwartz, 2020).

On the other hand, positive effects from training professionals working autistic individuals are reported for teachers (Corona, Christodulu, & Rinaldi, 2017; Leblanc, Richardson, & Burns, 2009) physicians (Kairys & Petrova, 2016) and mental health professionals (Murray, Spain, Williams, & Ryley, 2011). Increased knowledge and skills, through autism specific training for teachers, physicians, mental health professionals and other service providers is essential for providing quality services to clients. Training at the university level or in-service training can reduce misconceptions and improve service quality among future service providers. Additional funding is necessary for training staff, increasing

staff salaries, opening new positions, and offering new types of services, and hence can be a factor for improving all aspects of accessibility, availability and quality issues described in this study.

Findings supporting the third theme emphasize that communities need greater understanding of the heterogeneity in the autism population as well as the changing support needs over time, in order to provide appropriate and meaningful education programs and community and health services to children and individuals across the life span.

Although the need for services and support remains or even increases, as children age options for transition-aged children are even scarcer. This finding adds to the documented low service utilization for adolescents and young adults (12 – 39 years), and corroborates findings from other high- income countries (Anderson, et al., 2018; Platos & Pisula, 2019; Shattuck, Wagner, Narendorf, Sterzing, & Hensley, 2011). Capacities of providers to deliver services to transition-aged youth and adults needs further development, comprising of developing autism specific programs and training to prepare providers to deliver these services. This includes social skills and communication training and speech and language therapy (Havlicek, Bilaver, & Beldon, 2016; Shattuck, et al., 2011) and vocational rehabilitation services (Taylor & Seltzer, 2012). Support in the social and communication skills domain is critically important for transition-aged youth, especially as many individuals face challenges with employment and navigate the socially demanding environments in the workplace. During the transition into adulthood, more effective resources and services are necessary to plan for employment, housing, and independence that are meaningful to the individual, along with effective interventions, services and supports throughout their lifetime. Research has found that fewer than half of adults with autism are employed and those who are employed are underutilized or underpaid, which presents a barrier to achieving financial independence (Howlin & Moss, 2012).

The need for a more flexible and individually tailored approach in service provision dominated in the experiences of the caregivers. Individualized and person-centered approach in service provision is considered instrumental in providing appropriate and meaningful programs to meet holistic needs. These findings add to the previously established notion that individualization and personalization of support services is a crucial factor to promote health, equity and well-being of autistic persons (Gangadharan, Bhaumik, & Gumber, 2016).

Individualization of services inherently requires more parental input in educational planning and service planning in general. Currently, parents rarely see themselves in an equal relationship with

professionals. Partnership between families and professionals is an important factor to understanding the support needs, the issues influencing decisions about services, and can increase effectiveness and quality of support and services. Besides input from caregivers, a key consideration to the person-centered approach is meaningful participation of the individuals themselves, in decision-making and expressing aspirations and support needs. A shared decision-making approach is advocated, based on a collaborative framework between autistic individuals, their families, and service providers (Lai, Anagnostou, Wiznitzer, Allison, & Baron-Cohen, 2020) in order to enhance individual's outcomes. This corresponds with the imperative to devise truly participatory mechanisms attentive to the diversity of voices within the autistic community in the 'autistic voice' discourse (Milton, Mills, & Pellicano, 2014).

Limitations

Although, insights from key stakeholders' viewpoint represent indispensable considerations, qualitative feedback from professionals can illuminate how systemic barriers and support influence service provision abilities. Such findings may be highly relevant for policy and program development based on this population's needs. However, experiences originating from several different countries and systems were merged in constructed general impressions. How different systems influenced support perceptions was not taken in account. Diagnosis were self-reported, however this practice has been previously accepted, based on good agreement between self- and clinician report (Daniels et al., 2011). The sample was not stratified by severity level of the condition, the persons' cognitive or verbal abilities, or the number of needed services. All of these factors could potentially influence the experiences of support and service provision. Future research should explore how different service delivery systems affect support experiences of various groups of autistic individuals and their families.

Conclusion

The findings from this study supplement the literature specific to South and South-Eastern Europe, by exposing the problems related to meeting the needs of autistic children and youth and potential ways to improve services, as perceived by parents. The findings have potential policy ramifications for the region in which the research was conducted. Support systems need to provide continuous services across the lifespan, flexible enough to respond to the individual and family needs that are modifying over time. At the same time, service providers need to enhance autism skills and relational competences and address accessibility and eligibility issues. Adopting a shared decision-making

approach can provide a collaborative framework between autistic individuals, their families, and service providers for advancing autism services and support in the region.

Acknowledgments

The authors would like to thank Natalia Petrevska, graduate student from the Institute of Special Education and Rehabilitation, Faculty of Philosophy in Skopje for her assistance in recruiting participants. Our gratitude is also extended to the children and families with autism, school principals and staff from all countries involved in the study that made this research possible.

Ethics

Ethical approval for this study was obtained from University Ss. Cyril and Methodius Institutional Review Board. All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The research complies with The General Data Protection Regulation 2016/679 in EU law and The European Code of Conduct for Research Integrity.

Conflict of interests

Authors declare no conflict of interests.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the Erasmus Plus Programme of the European Commission [2018-1-EL01-KA204-047788].

References

- Anderson, C., Lupfer, A., & Shattuck, P. T. (2018). Barriers to Receipt of Services for Young Adults With Autism. *Pediatrics*, *141*(Suppl 4), S300-S305. doi: 10.1542/peds.2016-4300G
- Baio, J., Wiggins, L., Christensen, D. L., Maenner, M. J., Daniels, J., Warren, Z., . . . White, T. (2018). Prevalence of autism spectrum disorder among children aged 8 years—autism and developmental disabilities monitoring network, 11 sites, United States, 2014. *MMWR Surveillance Summaries*, *67*(6), 1.
- Bejarano-Martín, Á., Canal-Bedia, R., Magán-Maganto, M., Fernández-Álvarez, C., Cilleros-Martín, M. V., Sánchez-Gómez, M. C., . . . Posada de la Paz, M. (2020). Early Detection, Diagnosis and Intervention Services for Young Children with Autism Spectrum Disorder in the European Union (ASDEU): Family and Professional Perspectives. *Journal of autism and developmental disorders*, *50*(9), 3380-3394. doi: 10.1007/s10803-019-04253-0
- Borgi, M., Ambrosio, V., Cordella, D., Chiarotti, F., & Venerosi, A. (2019). Nationwide Survey of Healthcare Services for Autism Spectrum Disorders (ASD) in Italy. *Advances in Neurodevelopmental Disorders*, *3*(3), 306-318. doi: 10.1007/s41252-019-00113-1
- Braun, V., & Clarke, V. (2006). Using Thematic Analysis in Psychology. *Qualitative Research in Psychology*, *3*(2), 77-101. doi: 10.1191/1478088706qp063oa
- Chiri, G., & Warfield, M. E. (2012). Unmet Need and Problems Accessing Core Health Care Services for Children with Autism Spectrum Disorder. *Maternal and Child Health Journal*, *16*(5), 1081-1091. doi: 10.1007/s10995-011-0833-6
- Cidav, Z., Lawer, L., Marcus, S. C., & Mandell, D. S. (2013). Age-Related Variation in Health Service Use and Associated Expenditures Among Children with Autism. *Journal of autism and developmental disorders*, *43*(4), 924-931. doi: 10.1007/s10803-012-1637-2
- Corona, L. L., Christodulu, K. V., & Rinaldi, M. L. (2017). Investigation of School Professionals' Self-Efficacy for Working With Students With ASD: Impact of Prior Experience, Knowledge, and Training. *Journal of Positive Behavior Interventions*, *19*(2), 90-101. doi: 10.1177/1098300716667604
- Dababnah, S. (2018). Providers' Perspectives on Autism Service Access in the West Bank: an Application of the Three Delays Model. *Global Social Welfare*, *5*(1), 1-10. doi: 10.1007/s40609-017-0088-2
- Daniels, A. M., Como, A., Hergüner, S., Kostadinova, K., Stosic, J., & Shih, A. (2017). Autism in Southeast Europe: A Survey of Caregivers of Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, *47*(8), 2314-2325. doi: 10.1007/s10803-017-3145-x
- Daniels, A. M., Rosenberg, R. E., Law, J. K., Lord, C., Kaufmann, W. E., & Law, P. A. (2011). Stability of Initial Autism Spectrum Disorder Diagnoses in Community Settings. *Journal of Autism and Developmental Disorders*, *41*(1), 110-121. doi: 10.1007/s10803-010-1031-x
- DePape, A. M., & Lindsay, S. (2015). Parents' Experiences of Caring for a Child with Autism Spectrum Disorder. *Qualitative Health Research*, *25*(4), 569-583. doi: 10.1177/1049732314552455

- Dymond, S. K., Gilson, C. L., & Myran, S. P. (2007). Services for Children With Autism Spectrum Disorders. *Journal of Disability Policy Studies, 18*(3), 133-147. doi: 10.1177/10442073070180030201
- Gangadharan, S., Bhaumik, S., & Gumber, R. (2016). Supporting Young Adults with Autism Spectrum Disorders (ASD) to Maximise Their Potential. *Journal of Psychosocial Rehabilitation and Mental Health, 3*(1), 5-8. doi: 10.1007/s40737-016-0047-8
- Ghanouni, P., Jarus, T., Zwicker, J. G., Lucyshyn, J., Chauhan, S., & Moir, C. (2019). Perceived Barriers and Existing Challenges in Participation of Children with Autism Spectrum Disorders: "He Did Not Understand and No One Else Seemed to Understand Him". *Journal of Autism and Developmental Disorders, 49*(8), 1-10. doi: 10.1007/s10803-019-04036-7
- Grasu, M. (2018). Parents against autism spectrum disorders. *Buletin de Psihiatrie Integrativa, 76*(1), 39-48.
- Hansen, B. D., Orton, E. L., Adams, C., Knecht, L., Rindlisbaker, S., Jurtoski, F., & Trajkovski, V. (2017). A Pilot Study of a Behavioral Parent Training in the Republic of Macedonia. *Journal of autism and developmental disorders, 47*(6), 1878-1889. doi: 10.1007/s10803-017-3112-6
- Havlicek, J., Bilaver, L., & Beldon, M. (2016). Barriers and Facilitators of the Transition to Adulthood for Foster Youth with Autism Spectrum Disorder: Perspectives of Service Providers in Illinois. *Children and Youth Services Review, 60*, 119-128. doi: 10.1016/j.childyouth.2015.11.025
- Hendricks, D. (2011). Special Education Teachers Serving Students with Autism: A Descriptive Study of the Characteristics and Self-Reported Knowledge and Practices Employed. *Journal of Vocational Rehabilitation, 35*. doi: 10.3233/jvr-2011-0552
- Hodgetts, S., Zwaigenbaum, L., & Nicholas, D. (2015). Profile and predictors of service needs for families of children with autism spectrum disorders. *Autism, 19*(6), 673-683. doi: 10.1177/1362361314543531
- Howlin, P., & Moss, P. (2012). Adults with Autism Spectrum Disorders. *The Canadian Journal of Psychiatry, 57*(5), 275-283. doi: 10.1177/070674371205700502
- Jarbrink, K. (2007). The Economic Consequences of Autistic Spectrum Disorder Among Children in a Swedish Municipality. *Autism, 11*(5), 453-463. doi: 10.1177/1362361307079602
- Jones, S., Bremer, E., & Lloyd, M. (2017). Autism Spectrum Disorder: Family Quality of Life While Waiting for Intervention Services. *Qualitative Life Research, 26*(2), 331-342. doi: 10.1007/s11136-016-1382-7
- Kairys, S. W., & Petrova, A. (2016). Role of Participation of Pediatricians in the "Activated Autism Practice" Program in Practicing Children With Autism Spectrum Disorders at the Primary Care Setting. *Global Pediatric Health, 3*, 2333794X16663544. doi: 10.1177/2333794x16663544
- Kevan, F. (2003). Challenging Behaviour and Communication Difficulties. *British Journal of Learning Disabilities, 31*(2), 75-80. doi: 10.1046/j.1468-3156.2003.00226.x
- Khanlou, N., Haque, N., Mustafa, N., Vazquez, L. M., Mantini, A., & Weiss, J. (2017). Access Barriers to Services by Immigrant Mothers of Children with Autism in Canada. *International Journal of Mental Health and Addiction, 15*(2), 239-259. doi: 10.1007/s11469-017-9732-4

- Lai, M. C., Anagnostou, E., Wiznitzer, M., Allison, C., & Baron-Cohen, S. (2020). Evidence-Based Support for Autistic People Across the Lifespan: Maximising potential, Minimising barriers, and Optimising the Person-Environment Fit. *Lancet Neurology*. doi: 10.1016/s1474-4422(20)30034-x
- Leblanc, L., Richardson, W., & Burns, K. A. (2009). Autism Spectrum Disorder and the Inclusive Classroom: Effective Training to Enhance Knowledge of ASD and Evidence-Based Practices. *Teacher Education and Special Education, 32*(2), 166-179. doi: 10.1177/0741932507334279
- Liptak, G. S., Stuart, T., & Auinger, P. (2006). Health Care Utilization and Expenditures for Children with Autism: Data from U.S. National Samples. *Journal of autism and developmental disorders, 36*(7), 871-879. doi: 10.1007/s10803-006-0119-9
- Locke, J., Kang-Yi, C. D., Pellicchia, M., Marcus, S., Hadley, T., & Mandell, D. S. (2017). Ethnic Disparities in School-Based Behavioral Health Service Use for Children With Psychiatric Disorders. *J Sch Health, 87*(1), 47-54. doi: 10.1111/josh.12469
- McClain, M. B., Harris, B., Haverkamp, C. R., Golson, M. E., & Schwartz, S. E. (2020). The ASKSP Revised (ASKSP-R) as a Measure of ASD Knowledge for Professional Populations. *Journal of Autism and Developmental Disorders, 50*(3), 998-1006. doi: 10.1007/s10803-019-04321-5
- McLennan, J. D., Huculak, S., & Sheehan, D. (2008). Brief Report: Pilot Investigation of Service Receipt by Young Children with Autistic Spectrum Disorders. *Journal of Autism and Developmental Disorders 38*(6), 1192-1196. doi: 10.1007/s10803-007-0535-5
- Milton, D., Mills, R., & Pellicano, E. (2014). Ethics and Autism: Where is the Autistic Voice? Commentary on Post et al. *Journal of Autism and Developmental Disorders, 44*(10), 2650-2651. doi: 10.1007/s10803-012-1739-x
- Murray, M. M., Spain, K., Williams, E. U., & Ryley, A. T. (2011). Knowledge is Power: Empowering the Autism Community Through Parent-Professional Training. *The School Community Journal, 21*, 19-36.
- Oswald, D. P., Haworth, S. M., Mackenzie, B. K., & Willis, J. H. (2017). Parental Report of the Diagnostic Process and Outcome: ASD Compared With Other Developmental Disabilities. *Focus on Autism and Other Developmental Disabilities, 32*(2), 152-160. doi: 10.1177/1088357615587500
- Platos, M., & Pisula, E. (2019). Service use, Unmet needs, and Barriers to Services Among Adolescents and Young Adults with Autism Spectrum Disorder in Poland. *BMC Health Serv Res, 19*(1), 587. doi: 10.1186/s12913-019-4432-3
- Rogers, C. L., Goddard, L., Hill, E. L., Henry, L. A., & Crane, L. (2016). Experiences of diagnosing autism spectrum disorder: A survey of professionals in the United Kingdom. *Autism, 20*(7), 820-831. doi: 10.1177/1362361315611109
- Salomone, E., Beranová, Š., Bonnet-Brilhault, F., Briciet Lauritsen, M., Budisteanu, M., Buitelaar, J., . . . Charman, T. (2016). Use of Early Intervention for Young Children with Autism Spectrum Disorder Across Europe. *Autism, 20*(2), 233-249. doi: 10.1177/1362361315577218
- Sanz Cervera, P., Fernandez, I., Pastor, G., & Tarraga-Minguez, R. (2017). Pre-Service Teachers' Knowledge, Misconceptions and Gaps About Autism Spectrum Disorder. *Teacher Education and Special Education, 40*, 088840641770096. doi: 10.1177/0888406417700963

- Schreibman, L., Dawson, G., Stahmer, A. C., Landa, R., Rogers, S. J., McGee, G. G., . . . Halladay, A. (2015). Naturalistic Developmental Behavioral Interventions: Empirically Validated Treatments for Autism Spectrum Disorder. *Journal of autism and developmental disorders*, 45(8), 2411-2428. doi: 10.1007/s10803-015-2407-8
- Schwartz, H., & Drager, K. D. (2008). Training and Knowledge in Autism Among Speech-Language Pathologists: a Survey. *Lang Speech Hear Serv Sch*, 39(1), 66-77. doi: 10.1044/0161-1461(2008/007)
- Shattuck, P. T., Wagner, M., Narendorf, S., Sterzing, P., & Hensley, M. (2011). Post-High School Service Use Among Young Adults with an Autism Spectrum Disorder. *Arch Pediatr Adolesc Med*, 165(2), 141-146. doi: 10.1001/archpediatrics.2010.279
- Stahmer, A., Vejnosa, S., Iadarola, S., Straiton, D., Reinos Segovia, F., Luelmo, P., . . . Kasari, C. (2019). Caregiver Voices: Cross-Cultural Input on Improving Access to Autism Services. *Journal of Racial and Ethnic Health Disparities*, 6. doi: 10.1007/s40615-019-00575-y
- Stylianou, A. (2017). *Mothers with disabled children in Cyprus: experiences and support*. UCL (University College London).
- Taylor, J. L., & Seltzer, M. M. (2012). Developing a Vocational Index for Adults with Autism Spectrum Disorders. *J Autism Dev Disord*, 42(12), 2669-2679. doi: 10.1007/s10803-012-1524-x
- Thomas, K. C., Ellis, A. R., McLaurin, C., Daniels, J., & Morrissey, J. P. (2007). Access to Care for Autism-Related Services. *Journal of Autism and Developmental Disorders* 37(10), 1902-1912. doi: 10.1007/s10803-006-0323-7
- Vasilevska Petrovska, I., Giannakopoulou, A., Giannakopoulou, A., Winstanley, A., Miletto, R., Roşca, G., . . . Trajkovski, V. (2019). Environmental Barriers and Facilitators to Participation of People with Autism Spectrum Disorders: Stakeholders' Perspective. *Journal for ReAttach Therapy and Developmental Diversities*, 2, 26-39. doi: 10.26407/2019jrtd.1.19
- Veroni, E. (2019). The social stigma and the challenges of raising a child with autism spectrum disorders (ASD) in Greece. *Exchanges: The Interdisciplinary Research Journal*, 6(2), 1-29.
- Zelege, W. A., Hughes, T. L., & Drozda, N. (2019). Disparities in Diagnosis and Service Access for Minority Children with ASD in the United States. *J Autism Dev Disord*, 49(10), 4320-4331. doi: 10.1007/s10803-019-04131-9
- Zerbo, O., Massolo, M. L., Qian, Y., & Croen, L. A. (2015). A Study of Physician Knowledge and Experience with Autism in Adults in a Large Integrated Healthcare System. *Journal of Autism and Developmental Disorders*, 45(12), 4002-4014. doi: 10.1007/s10803-015-2579-2
- Zwaigenbaum, L., Bauman, M. L., Choueiri, R., Kasari, C., Carter, A., Granpeesheh, D., . . . Natowicz, M. R. (2015). Early Intervention for Children With Autism Spectrum Disorder Under 3 Years of Age: Recommendations for Practice and Research. *Pediatrics*, 136(Supplement 1), S60-S81. doi: 10.1542/peds.2014-3667E