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Pain, dietary habits and physical activity of children with developmental disabilities in Croatia, North Macedonia and Serbia: a cross-sectional study

Jelena Međaković[1], Antonia Čivljak[2], Tatjana Zorčec[3], Vesna Vučić[4], Danijela Ristić-Medić[4], Aleksandra Veselinović[5,6], Marta Čivljak[1] and Livia Puljak[7*]

Abstract

Background Multiple studies have shown that children with developmental disabilities (CDD) often live with unrecognized and untreated pain, consume inadequate diet and have inadequate levels of physical activity. This study aimed to analyze pain, dietary habits and physical activity of CDD in Croatia, North Macedonia and Serbia.

Methods A cross-sectional study was conducted in Croatia, North Macedonia and Serbia in March–April 2023 within the Erasmus+ SynergyEd project. The study included parents and caregivers of CDD. Data were collected via online survey.

Results We included 954 participants from Croatia (*N*=543; 57%), North Macedonia (*N*=205; 21%) and Serbia (*N*=206; 22%). Participants reported that 16% of children suffered from chronic pain related to their condition.

The main findings of our study are that chronic pain is prevalent in CDD (16%). Almost half (48%) of participants avoid certain foods for their children. The majority of children (86%) were not on a special diet. Among those that were on a special diet, they were most commonly (60%) on a gluten-free diet. Most (54%) participants stated that their children used nutritional supplements. Less than half participants (45%) stated that the child is involved in some kind of physical activity. Only 17% of CDD engaged in physical activities 5 h or more per week.

Conclusion Our findings indicate that chronic pain, inadequate dietary patterns and insufficient physical activity are common in CDD from Croatia, Macedonia and Serbia. Education of parents and caregivers can mitigate their use of interventions that have not been proven effective, such as for example the use of gluten-free diets in CDD.

Keywords Children with developmental disabilities, Pain, Nutrition, Physical activity

*Correspondence:
Livia Puljak
livia.puljak@unicath.hr; livia.puljak@gmail.com
Full list of author information is available at the end of the article

Background

Children with developmental disabilities (CDD) have various conditions that require healthcare and related services of a kind or magnitude greater than in typically developing children [1]. Children with developmental disabilities highly depend on their parents for the fulfillment of their needs. However, multiple studies have shown that parents and caregivers of CDD are often insufficiently informed on the children's needs regarding nutrition [2], dietary supplementation [3], physical activity [4], or pain management [5].

Children's physical and cognitive development is greatly influenced by their nutrition, which may also affect how well they perform in school [6]. While concerns about children's general access to healthy food and nutrition have received attention [7], conversations about the dietary requirements of children with disabilities are uncommon, hard to find, and disorganized. It has been shown in multiple studies that the diets of children with disabilities need improvement [3, 8, 9]. For example, supplement use continues to be a prevalent form of complementary and alternative therapy used in autism spectrum disorders (ASD). However, even though a multitude of supplements and dietary interventions are utilized in children with ASD, the scientific consensus remains that there is currently little evidence to support the use of such interventions for children with ASD [3]. Bendini et al. showed that children with intellectual disabilities lacked adequate intake of various nutrients [8]. Dietary excesses and overweight/obesity were commonly found in children with Down syndrome [9].

When it comes to physical activity, research results indicate that CDD spend more time in sedentary activities compared to their peers without disabilities [10]. A scoping review of 36 studies published in 2021 showed that sedentary behavior patterns were described in 29 studies, particularly in children with cerebral palsy [11]. Low levels of physical activity and sedentary behaviors, particularly those that are screen-based, were recorded among children with intellectual disabilities. Parents of children and adolescents with intellectual disabilities reported approximately 204 min/day of after-school sedentary behavior [12]. This can be due to parents choosing activities that do not present extensive social and physical demands for their child [13].

Pan et al. recently described that among youth with ASD aged 6–17 years, the average measured sedentary time was 650 min/day [14]. Another study conducted on students with developmental disabilities, including visual impairments, hearing impairments, physical disabilities, intellectual disabilities, and social developmental disabilities, indicated that children spent 70% of their day at school being sedentary [15]. Often, the disability itself, or medications used for its treatment, leads to inactivity and, consequently, reduced muscle function and fitness [16]. Yazdani et al. reported the following barriers to physical activity in CDD: the child's lack of interest, lack of developmentally appropriate programs for physical activity, too many behavioral problems, and parents' lack of time [17]. This is in line with the study of Columna et al., who reported that barriers hindering physical activity of CDD include inadequate programs, time, and/or disability [18].

Furthermore, CDD live with more pain than typically developing children because of chronic physical problems, complex medical conditions, and more frequent injuries and medical procedures [19]. Recognition of pain in CDD can also be a challenge if the CDD cannot report pain due to children's limited communication abilities [20]. Difficult pain assessment and lack of knowledge among healthcare workers have been recognized as ongoing barriers to effective pain management in CDD [21].

However, there is a paucity of data about nutrition, physical activity and the prevalence of pain in CDD from Eastern Europe. Therefore, this study aimed to survey parents and caregivers to analyze pain, dietary habits and physical activity of CDD in Croatia, North Macedonia and Serbia.

Methods

Study design

We conducted a cross-sectional study using an online survey in Croatia, North Macedonia, and Serbia within the Erasmus + SynergyEd project [22].

Ethics

The Ethics Committee of the Catholic University of Croatia approved the study protocol prospectively on March 3, 2023 (Classification number: 641–03/23–03/045; Registration number: 498–15-06–23-002). We conducted all methods in line with the relevant guidelines and regulations. Before taking part in the study, participants received detailed information about the study via email. At the first page of the online survey interface, the participants were asked to indicate their written informed consent.

Reporting

The Checklist for Reporting Results of Internet E-Surveys (CHERRIES) was used to report this study [23].

Participants

The following inclusion criteria were applied: caregivers of CDD in Croatia, North Macedonia, and Serbia. We defined caregivers as any individual with parenting

or caring responsibility for CDD. Children were defined as individuals younger than 18 years [24]. Children with developmental disabilities were defined as having an increased risk of chronic physical, developmental, behavioral, or emotional conditions, requiring healthcare and related services beyond that required by children that develop typically [1]. Exclusion criteria were not defined.

We contacted eligible participants through nongovernmental organizations of parents and caregivers of CDD. We used a snowballing method. When we contacted organizations catering to parents/caregivers of CDD, we asked them to forward the invitation to participate in the study to their members. Also, in the invitation, participants were encouraged to share the invitation with other individuals who fulfilled the inclusion criteria.

Individuals that accepted to participate in the study were kindly asked if they can invite additional eligible individuals. Invitations were sent via e-mail using the text provided in Supplementary file 1 (available online at https://osf.io/c6w5b/). Information sheet with details about the study was enclosed with the message, as well as a link to the online survey. We sent two reminders to the participants, the first one was sent 2 weeks after the initial invitation and the second one 4 weeks after the initial invitation. We did not offer participants any kind of incentives. The participation was voluntary and anonymous.

Survey

In this study, we used a survey with questions on pain, dietary habits, and physical activity of CDD, together with sociodemographic questions about the parents/caregivers. These questions were a part of the broader survey, which was a modified and expanded version of the Caregiver Needs Survey. The full text of the survey in the English language is available in Supplementary file 2 (available online at https://osf.io/c6w5b/). Modifications and additions to the original survey are described in Supplementary file 3 (available online at https://osf.io/c6w5b/). Surveys were distributed via SurveyMonkey in three different languages – Croatian, Macedonian and Serbian. Surveys in these three languages are available in Supplementary files 4–6 (available online at https://osf.io/c6w5b/). We used translation already made for the Serbian language in the literature [25] and made adjustments for Macedonian and Croatian languages.

In SurveyMonkey, the survey was organized into 26 pages. Skip logic was used to direct participants toward subsequent questions based on their prior answers. The participants were able to revise their questions. Cookies were not used to assign a unique user identifier to participants' devices. We did not collect participants' personal identifiers, such as their names and email addresses. We did not collect the participants' IP addresses. Techniques to try to prevent duplicate entries were not used. We did not ask participants for registration. The survey used in this study was not under password protection.

Development and testing of the survey

After developing the initial version of the survey in SurveyMonkey, we conducted pilot testing on a sample of five individuals who met the eligibility criteria. Pilot testers were asked to assess the usability and technical functionality of the online survey. We did not include the responses of pilot testers in the main study sample because they provided feedback and suggestions for revisions, which we took into account for revising the survey.

Data analysis

All surveys were analyzed. We did not exclude any surveys based on incomplete answers, early terminations, or time spent in the survey. Corrections or revisions of the participants' raw data were not made. From the SurveyMonkey website, we extracted raw data. Descriptive statistics were analyzed using MedCalc software (Ostend, Belgium). In our study protocol, we planned to censor any identifying data if the participants provided them in the open-ended questions. However, we did not find any such identifying details while analyzing the data.

Continuous data were tested for normality using the Kolmogorov–Smirnov test. This test showed that none of the continuous data variables were normally distributed. Those data were presented as the median and interquartile range (IQR).

We analyzed open-ended questions using a qualitative description (QD) method [26]. Qualitative description is a research approach involving a descriptive summary of the data collected without an attempt to reinterpret the participants' comments. The QD approach was considered appropriate for our study because our qualitative data mainly consisted of succinct, open-ended statements, which allowed us to avoid trying to reinterpret participant comments. In our study, two authors (AC and LP) were involved in QD. Open-ended responses were reviewed and coded. Author AC suggested the codes, and author LP verified them. Coding definitions were applied to the data through an iterative process until a consensus was reached about the final coding categories.

Data availability

The raw data collected in this study were made public on Open Science Framework (link: https://osf.io/chxyr/), with the exception of indirect identifiers, i.e., participants' demographic information.

Results

We included 954 parents/caregivers of CDD from Croatia (*N*=543; 57%), North Macedonia (*N*=205; 21%), and Serbia (*N*=206; 22%). The majority of participants (56%) had a secondary education, followed by a university degree (*N*=299; 31%), primary school (*N*=63; 6.6%), and a Master's or PhD degree (*N*=56; 5.9%). The median participants' age was 38 years (IQR: 9). The median age of their children with disabilities was 7 (IQR: 8). Median number of CDD taken care of by the participants was 1 (IQR: 0).

The most common diagnosis of participants' children was autism spectrum disorder (*N*=248; 26%), followed by disorders of speech, language, and communication (*N*=101; 11%), cerebral paralysis and other paralytic/plegic disorders (*N*=87; 9.1%), epilepsy (*N*=65; 6.8%), congenital malformations of the nervous system (*N*=54; 5.6%), hiperkinetic disorders (*N*=52; 5.5%), mixed specific developmental disorders / disharmonious development (*N*=51 (5.3%), delay or absence of the expected stage of development (*N*=40; 4.2%), intellectual disabilities (*N*=39; 4.1%), Down syndrome (*N*=33; 3.5%) and other. Most children were male (*N*=504; 69%), with the median age of 7 years.

Pain

Participants indicated that chronic pain associated with the underlying condition that causes developmental disabilities was experienced by 16% of the children (Table 1). Most of them (31%) stated that this pain occurs less than once a week and most often (44%) appears on multiple body parts. Most participants (54%) reported that their child takes medication for pain relief. In Croatia, 21% of children take pain medications, while in North Macedonia, this percentage was more than three times higher. Pain-relief medicine was most (52%) often prescribed by a specialist physician. In Serbia, specialists and primary care physicians prescribe medicines on similar terms (40% vs 40%). Children most commonly took ibuprofen and paracetamol (Table 1).

Food and eating habits

In the part of the survey related to food and eating habits, most participants (37%) stated that their child eats four times a day. In North Macedonia, 52% of children regularly had three meals a day, compared to just 22% in Croatia. In Serbia, a larger proportion of children ate vegetables than in the other two countries, while in Croatia 14% of children did not eat vegetables. Children in Serbia had the highest consumption of bread and the lowest intake of sweets. Less than half of children (39%) drank soft drinks/or sweet beverages. The lowest percentage of children who completely avoided soft drinks is 25%, and was observed in Croatia. When asked about the description of the child's appetite, the most common answer (34%) was that the child's appetite is good or fair. Children most often (62%) did not have rituals during meals. When they had such rituals, the most common (43%) was placing toys or other objects on the table (Table 2).

Almost half (48%) of participants avoid certain foods for their children (Table 3). Among the offered responses, most participants chose milk (34%). In an open-ended answer option, most participants wrote that they avoid sweets. In a country comparison, Serbia had the highest percentage of children who do not consume milk at 51%, while Croatia had the lowest at 22% (Table 3). When asked for the reason why they avoid those foods, the majority gave a non-specific response that this is due to the child's underlying disease, or they considered the food unhealthy, or the child refused the food (Table 4).

Most participants stated that their child did not have a food allergy (90%). The foods most often cited as an allergen were milk (44%), peanuts (31%) and eggs (30%) (Table 5). Milk was reported as the most common allergen by 63% of parents in Serbia. In Croatia, eggs were mentioned as allergens by 38% of parents and peanuts by 49%.

The majority of children (86%) were not on a special diet (Table 6). Children who are on special diets were most often on gluten-free diet (60%). 79% of parents in Serbia stated that their children ate a gluten-free diet, compared to 54% in North Macedonia and 42% in Croatia. In North Macedonia, 90% of children followed a lactose-free diet, whereas in Serbia, 64% were on a dairy-free diet.

A physician most often (44%) prescribed a special diet. However, some special diets were prescribed also by a provider of alternative medicine services (homeopath), a psychologist and a speech therapist. Approximately 22% of parents introduced a special diet for their children on their own initiative without consulting a physician or nutritionist (Table 6).

Most (54%) participants stated that their children used dietary supplements (Table 7). The most common answer is that the child uses vitamins (77%) and probiotics (47%), with the variety of other supplements used (Tables 7 and 8). In North Macedonia, 90% of parents reported that their children take vitamins. Those supplements were most commonly (48%) prescribed by a specialist physician (Table 7). Only 4 (0.4%) participants indicated that a nutritionist prescribed the supplements. Some participants indicated that alternative medicine practitioners prescribed the supplements (Table 7). For participants who answered the question about other dietary supplements that the child takes, the most common answer was that they take Omega-3 and fish oil (Table 8).

Table 1 Frequency and characteristics of children's chronic pain

Questions	N (%)			
	Croatia	North Macedonia	Serbia	Total
Does your child experience any physical pain related to an underlying condition/problem causing the developmental difficulties, which is long-term (chronic) and lasts for 3 months or longer?				
Yes	74 (19)	28 (16)	13 (7.7)	115 (16)
No	244 (62)	110 (64)	127 (75)	481 (66)
Don't know	73 (19)	33 (19)	30 (18)	136 (19)
How often does your child feel physical pain?				
Every day	18 (25)	10 (36)	6 (40)	34 (30)
Several times a week	19 (26)	8 (29)	4 (27)	31 (27)
Once a week	13 (18)	1 (3.6)	0 (0)	14 (12)
Less than once a week	22 (31)	9 (32)	5 (33)	36 (31)
In which part of the body does the pain occur?				
Head	19 (26)	6 (21)	3 (20)	28 (24)
Neck	3 (4.2)	0 (0)	0 (0)	3 (2.6)
Hands	2 (2.8)	0 (0)	0 (0)	2 (1.7)
Body	6 (8.3)	0 (0)	4 (27)	10 (8.7)
Legs	11 (15)	8 (29)	2 (13)	21 (18)
Multiple body parts	31 (43)	14 (50)	6 (40)	51 (44)
Do you use any medications to resolve this pain?				
Yes	37 (21)	19 (68)	6 (40)	62 (54)
No	35 (49)	9 (32)	9 (60)	53 (46)
Don't know	0 (0)	0 (0)	0 (0)	0 (0)
Who prescribed those medicines?				
Specialist (pediatrician, cardiologist, rheumatologist, traumatologist etc.)	21 (60)	8 (42)	2 (40)	31 (53)
Primary care physician/Family physician	11 (31)	5 (26)	2 (40)	18 (31)
Somebody else	3 (8.6)	6 (32)	1 (20)	10 (17)
Which pain-relief medicines is your child taking?				
Ibuprofen	14 (2.6)	7 (3.4)	3 (1.5)	24 (2.5)
Paracetamol	10 (1.9)	7 (3.4)	0 (0)	17 (1.8)
Muscle relaxant (diazepam, baclofen, etc.)	2 (0.4)	3 (1.5)	1 (0.5)	6 (0.6)
Naproxen sodium	2 (0.4)	1 (0.5)	0 (0)	3 (0.3)
Diclofenac sodium	2 (0.4)	0 (0)	0 (0)	2 (0.2)
Topiramate	1 (0.2)	0 (0)	0 (0)	1 (0.1)

Physical activity

Less than half of theparticipants (45%) stated that the child was involved in some physical activity (Table 9). Those that did engage in physical acvitiy performed it most often for 2–3 h per week. There were 17% of children engaged in physical activities 5 h or more per week (Table 9).

Discussion

The main findings of our study are that chronic pain is prevalent in CDD (16%), almost half (48%) of participants avoid certain foods for their children, the majority of children (86%) were not on a special diet and most (54%) participants stated that their children used nutritional supplements. Less than half of the participants (45%) stated that the child is involved in some kind of physical activity. Only 17% of CDD were engaged in physical activities 5 h or more per week.

Pain

It is estimated that children with intellectual and developmental disabilities have more than twice the incidence of chronic pain compared to their typically developing peers. Indeed, a systematic review published in 2022, which analyzed 27 studies conducted in low- and middle-income countries (LMIC), showed that a pooled mean

Table 2 Children's eating habits

Questions	N (%)			
	Croatia	North Macedonia	Serbia	Total
How many times does your child usually eat per day?				
Once	0 (0)	2 (1.2)	0 (0)	2 (0.3)
Twice	8 (2.1)	7 (4.1)	3 (1.8)	18 (2.6)
Three times	80 (21)	88 (52)	49 (29)	217 (30)
Four times	130 (35)	54 (32)	76 (45)	260 (37)
Five times	84 (22)	11 (6.5)	27 (16)	122 (17)
More than five times	72 (19)	7 (4.1)	14 (8.3)	93 (13)
Child's particular eating habits				
Experiences feelings of hunger during the day				
Yes	192 (51)	62 (37)	90 (53)	344 (48)
Sometimes	126 (34)	61 (36)	61 (36)	248 (35)
No	56 (15)	46 (27)	18 (11)	120 (17)
Eats a good breakfast				
Yes	253 (68)	125 (74)	120 (71)	498 (70)
Sometimes	97 (26)	31 (18)	42 (25)	170 (24)
No	24 (6.4)	13 (7.7)	7 (4.1)	44 (6.2)
Eats meat				
Yes	274 (73)	114 (67)	127 (75)	515 (72)
Sometimes	70 (19)	37 (22)	28 (17)	135 (19)
No	30 (8.0)	18 (11)	14 (8.3)	62 (8.7)
Eats vegetables				
Yes	239 (64)	110 (65)	122 (72)	471 (66)
Sometimes	92 (25)	35 (21)	35 (21)	162 (23)
No	43 (12)	24 (14)	12 (7.1)	79 (11)
Eats fruits				
Yes	258 (70)	116 (69)	120(71)	494 (69)
Sometimes	65 (17)	39 (23)	34 (20)	138 (19)
No	51 (14)	14 (8.3)	15 (8.9)	80 (11)
Eats dairy products				
Yes	265(71)	121 (72)	95 (56)	481 (67)
Sometimes	73 (20)	37 (22)	36 (21)	146 (21)
No	36 (9.6)	11 (6.5)	38 (22)	85 (12)
Eats cereals (bread, pasta, rice and baked products)				
Yes	294(79)	147 (87)	111 (66)	552 (78)
Sometimes	61 (16)	17 (10)	37 (22)	115 (16)
No	19 (5.1)	5 (2.9)	21 (12)	45 (6.3)
Eats sweets				
Yes	217 (58)	95 (56)	61 (36)	373 (52)
Sometimes	123 (33)	47 (28)	71 (42)	241 (34)
No	34 (9.1)	27 (16)	37 (22)	98 (14)
Drinks soft drinks/or sweet beverages				
Yes	158 (42)	61 (36)	56 (33)	275 (39)
Sometimes	124 (33)	50 (30)	47 (28)	221 (31)
No	92 (25)	58 (34)	66 (39)	216 (30)
Can you describe your child's appetite?				
Good	129 (34)	66 (39)	45 (27)	240 (34)
Fair	130 (35)	62 (37)	75 (44)	267 (38)
Poor	16 (4.3)	6 (3.6)	7 (4.1)	29 (4.1)

Table 2 (continued)

Questions	N (%)			
	Croatia	North Macedonia	Serbia	Total
Picky	99 (26)	35 (21)	42 (25)	176 (25)
Does your child have mealtime rituals or restrictions (e.g., putting toys or other objects on the table, eating only in the presence of certain conditions, and being very selective about the consistency or color of food and the presentation of food in plate)				
Yes	172(46)	44 (26)	53 (31)	269(38)
No	202(54)	125 (74)	116(69)	443(62)
What rituals or restrictions does your child have during meals (multiple answer were allowed):				
Placing toys or other objects on the table	83 (49)	13 (30)	17 (32)	113(43)
Eating only under certain conditions	43 (25)	12 (27)	10 (19)	65 (24)
Very picky about the consistency or color of food	76 (45)	20 (45)	19 (36)	115(43)
Great pickiness regarding the presentation of the food on the plate	36 (21)	12 (27)	9 (17)	57 (21)
Something else	26 (15)	13 (30)	17 (32)	56 (22)

Table 3 Food that parents/caregivers avoid for the child (open-ended responses for the answer "Something else")

Questions	N (%)			
	Croatia	North Macedonia	Serbia	Total
Do you avoid any food for your child?				
Yes	166 (45)	84 (50)	90 (53)	340 (48)
No	204 (55)	85 (50)	79 (47)	368 (52)
Which food do you avoid for your child (multiple answer were allowed)?				
Milk	35 (22)	34 (40)	45 (51)	114 (34)
Eggs	26 (17)	13 (15)	10 (11)	49 (15)
Meat	12 (7.6)	13 (15)	8 (8.9)	33 (10)
Fruit	13 (8.3)	1 (1.2)	5 (5.6)	19 (5.7)
Vegetables	13 (8.3)	3 (3.5)	1 (1.1)	17 (5.1)
Something else	102 (65)	54 (64)	61 (69)	217 (66)
Other food that parents/caregivers avoid for the child (open-ended responses for the answer "Something else")				
Response	**Croatia N (%)**	**North Macedonia N (%)**	**Serbia N (%)**	**All N (%)**
Sweets	32 (5.9)	8 (3.9)	31 (15)	71 (7.4)
Sugar	10 (1.8)	10 (4.9)	7 (3.4)	27 (2.9)
Starch (rice, potatoes, bread, white flour)	12 (2.2)	6 (2.9)	8 (3.9)	26 (2.7)
Gluten	7 (1.3)	5 (2.4)	13 (6.3)	25 (2.6)
Meat products (salami, cold cuts, sausages, hot dogs, pate)	10 (1.8)	8 (3.9)	4 (1.9)	22 (2.3)
Sweetened or carbonated beverages	11 (2.1)	9 (4.4)	1 (0.5)	21 (2.2)
Fats and oils (sunflower, mayonnaise, margarine)	0 (0)	18 (8.8)	0 (0)	18 (1.9)
Salty snacks (chips, peanuts…)	5 (0.9)	4 (1.9)	7 (3.4)	16 (1.7)
Nuts	6 (1.1)	1 (0.5)	2 (0.9)	9 (0.9)
Preservatives and additives	0 (0)	3 (1.5)	4 (1.9)	7 (0.7)
Fast and canned food	3 (0.6)	3 (1.5)	0 (0)	6 (0.6)
Fish	0 (0)	4 (1.9)	0 (0)	4 (0.4)
Legumes (beans, green beans, peas)	3 (0.6)	0 (0)	1 (0.5)	4 (0.4)
Soybeans	1 (0.2)	1 (0.5)	1 (0.5)	3 (0.3)
Casein	1 (0.2)	0 (0)	1 (0.5)	2 (0.2)
Yeast	1 (0.2)	0 (0)	0 (0)	1 (0.1)
Alcohol	1 (0.2)	0 (0)	0 (0)	1 (0.1)
Purine	1 (0.2)	0 (0)	0 (0)	1 (0.1)

Table 4 Reasons why parents/caregivers avoid certain foods for a child

Response	Croatia N (%)	North Macedonia N (%)	Serbia N (%)	All N (%)
Due to the underlying disease	31 (5.7)	28 (14)	16 (7.8)	75 (7.9)
Parents consider foods unhealthy	29 (5.3)	22 (11)	22 (11)	73 (7.7)
Child refuses food	34 (6.3)	15 (7.3)	5 (2.4)	54 (5.7)
Changes in behavior after consumption	17 (3.1)	8 (3.9)	9 (4.3)	34 (3.6)
Gastrointestinal problems after consumption	18 (3.3)	3 (1.5)	95 (46)	30 (3.1)
Allergies	21 (3.9)	4 (1.9)	5 (2.4)	30 (3.1)
Candida (overcome or acute infection, fear of infection)	1 (0.2)	2 (0.9)	16 (7.8)	19 (2.0)
Due to excess body weight	8 (1.5)	4 (1.9)	2 (0.9)	14 (1.5)
Child consumes that food excessively	3 (0.6)	1 (0.5)	0 (0.0)	4 (0.4)
Due to therapy (contraindicated)	1 (0.2)	0 (0)	1 (0.5)	2 (0.2)
For no reason	1 (0.2)	1 (0.5)	0 (0)	2 (0.2)

Table 5 Food allergies of the children

Questions	N (%)			
	Croatia	North Macedonia	Serbia	Total
Does your child have any food allergies?				
Yes	37 (10)	15 (8.9)	19 (11)	71 (10)
No	324 (90)	154 (91)	148 (89)	626 (90)
To what food is your child allergic (multiple answer were allowed)?				
Cereals	6 (16)	2 (13)	5 (26)	13 (18)
Fish	1 (2.7)	2 (13)	1 (5.3)	4 (5.7)
Eggs	14 (38)	2 (13)	5 (26)	21 (30)
Milk	11 (30)	8 (53)	12 (63)	31 (44)
Red fruit	3 (8.1)	1 (6.7)	1 (5.3)	5 (7.0)
Peanuts	18 (49)	2 (13)	2 (11)	22 (31)
Walnuts	8 (22)	1 (6.7)	4 (21)	13 (18)
Soy	7 (19)	1 (6.7)	3 (16)	11 (16)
Kiwi	2 (5.4)	1 (6.7)	2 (11)	5 (7.0)
Something else	14 (38)	4 (27)	9 (47)	27 (38)
Other food that the child is allergic to (open-ended responses for the answer "Something else")				
Response	**Croatia N (%)**	**North Macedonia N (%)**	**Serbia N (%)**	**All N (%)**
Hazelnut	1 (0.2)	2 (0.9)	1 (0.5)	4 (0.4)
Almond	1 (0.2)	0 (0)	1 (0.5)	2 (0.2)
Preservatives and additives	2 (0.4)	0 (0)	0 (0)	2 (0.2)
Lemon	0 (0)	0 (0)	2 (0.9)	2 (0.2)
Orange	0 (0)	0 (0)	2 (0.9)	2 (0.2)
Lactose	0 (0)	1 (0.5)	1 (0.5)	2 (0.2)
Cocoa	1 (0.2)	0 (0)	1 (0.5)	2 (0.2)
Ketchup	1 (0.2)	0 (0)	1 (0.5)	2 (0.2)
Gluten	0 (0)	0 (0)	1 (0.5)	1 (0.1)
Beans	1 (0.2)	0 (0)	0 (0)	1 (0.1)
Blackberries	1 (0.2)	0 (0)	0 (0)	1 (0.1)
Honey	0 (0)	0 (0)	1 (0.5)	1 (0.1)
Chickpeas	0 (0)	1 (0.5)	0 (0)	1 (0.1)
Mint	0 (0)	1 (0.5)	0 (0)	1 (0.1)
Garlic	1 (0.2)	0 (0)	0 (0)	1 (0.1)
Cabbage	1 (0.2)	0 (0)	0 (0)	1 (0.1)

Table 6 Special diet of the children

Questions	N (%)			
	Croatia	North Macedonia	Serbia	Total
Is your child on some special diet (gluten free, lactose free, intermittent fasting, keto diet etc.)?				
Yes	34 (9.4)	22 (13)	42 (25)	98 (14)
No	327 (91)	147 (87)	125 (75)	599 (86)
On what special diet is your child (multiple answer were allowed)? (*N* = 98)				
Gluten-free diet	14 (41)	12 (55)	33 (79)	59 (60)
Lactose-free diet	9 (26)	20 (91)	21 (50)	20 (20)
Diet without dairy products	9 (26)	10 (45)	27 (64)	46 (47)
Diet without eggs	5 (15)	2 (9.1)	6 (14)	13 (13)
Hypoallergenic diet	1 (2.9)	0 (0)	1 (2.4)	2 (2.0)
Vegetarian diet	1 (2.9)	0 (0)	1 (2.4)	2 (2.0)
Vegan diet	0 (0)	0 (0)	0 (0)	0 (0)
Rotational diet	0 (0)	0 (0)	1 (2.4)	1 (1.0)
Elementary diet	0 (0)	0 (0)	0 (0)	0 (0)
Intermittent fasting	1 (2.9)	1 (4.6)	1 (2.4)	3 (3.0)
Keto diet	0 (0)	0 (0)	0 (0)	0 (0)
Macrobiotic nutrition	0 (0)	0 (0)	0 (0)	0 (0)
Something else	18 (53)	5 (23)	6 (14)	29 (30)
Who prescribed that special diet?				
Physician	17 (50)	11 (50)	15 (36)	43 (44)
Nutritionist	6 (18)	3 (14)	5 (12)	14 (14)
Nurse	0 (0)	0 (0)	0 (0)	0 (0)
No one prescribed a diet, we decided alone to use this type of diet	5 (15)	6 (27)	11 (26)	22 (22)
Someone else recommended this type of diet to you	6 (18)	2 (9.1)	11 (26)	19 (19)
Someone else:				
Provider of alternative medicine services (homeopath)	1 (0.2)	1 (0.5)	0 (0)	2 (0.2)
Psychologist	0 (0)	0 (0)	1 (0.5)	1 (0.1)
Speech therapist	0 (0)	0 (0)	1 (0.5)	1 (0.1)
Other special diets that are fed to the childdren (open-ended responses for the answer "Something else")				
Response	**Croatia N (%)**	**North Macedonia N (%)**	**Serbia N (%)**	**All N (%)**
Diet without sugar	1 (0.2)	1 (0.5)	2 (0.9)	4 (0.4)
Low-calorie diet (LCHF)	2 (0.4)	0 (0)	1 (0.5)	3 (0.3)
Milk substitutes	2 (0.4)	0 (0)	0 (0)	2 (0.2)
Mediterranean diet	1 (0.2)	1 (0.5)	0 (0)	2 (0.2)
Low-protein diet	2 (0.4)	0 (0)	0 (0)	2 (0.2)
Purine-free diet	2 (0.4)	0 (0)	0 (0)	2 (0.2)
Peptamen diet	1 (0.2)	0 (0)	0 (0)	1 (0.1)
Pediasure supplement	1 (0.2)	0 (0)	0 (0)	1 (0.1)
MM nutrition	0 (0)	0 (0)	1 (0.5)	1 (0.1)
Elementary formula	0 (0)	0 (0)	1 (0.5)	1 (0.1)
Raw food diet	1 (0.2)	0 (0)	0 (0)	1 (0.1)

of 8% chronic pain was estimated across all studies [27]. The authors warned that the characterization of pediatric chronic pain in LMIC suffers from a paucity of data [27], and our study is helping fill that gap. Based on the World Bank, Croatia is classified as a high-income economy; however, North Macedonia and Serbia are classified as upper-middle-income economies [28].

In our study, the prevalence of chronic pain among CDD was double that percentage – 16%. While our sample was heterogeneous and not restricted to a specific category of CDD, the results are concerning. These results point to the need for heightened awareness about chronic pain in children, its diagnosis, and treatment.

Table 7 Dietary supplements consumed by the children

Questions	N (%)			
	Croatia	North Macedonia	Serbia	Total
Does your child use any supplements (vitamins, minerals, probiotic, melatonin etc.….)?				
Yes	149 (41)	124 (73)	102 (61)	375 (54)
No	212 (59)	45 (27)	65 (39)	322 (46)
What kind of supplements does the child take (multiple answer were allowed)?				
Vitamins	97 (66)	112 (90)	79 (77)	288 (77)
Minerals	21 (14)	40 (32)	27 (26)	88 (24)
Probiotics	57 (39)	64 (52)	54 (53)	175 (47)
Melatonin	15 (10)	29 (23)	11 (11)	55 (15)
Other	29 (20)	27 (22)	21 (21)	77 (21)
Who prescribed those supplements?				
Specialist (pediatrician, cardiologist, rheumatologist, traumatologist etc.)	69 (47)	63 (51)	45 (44)	177 (48)
Primary care physician/Family physician	12 (8.2)	13 (10)	6 (5.9)	31 (8.3)
No one prescribed supplements, we decided that the child will start taking them	56 (38)	37 (30)	31 (30)	124 (33)
Someone else, who is not a physician, recommended taking these supplements:	9 (6.2)	11 (8.9)	20 (20)	40 (11)
Provider of alternative medicine services (homeopath, bioenergetic specialist)	2 (0.4)	1 (0.5)	3 (1.5)	6 (0.6)
Nutritionist	2 (0.4)	0 (0)	2 (0.9)	4 (0.4)
Pharmacist	1 (0.2)	1 (0.5)	0 (0)	2 (0.2)
Educational rehabilitator	0 (0)	1 (0.5)	0 (0)	1 (0.1)

Table 8 Other supplements that a child is taking (Responses for the answer Other)

Response	Croatia N (%)	North Macedonia N (%)	Serbia N (%)	All N (%)
Omega-3 and fish oils	8 (1.5)	7 (3.4)	10 (4.9)	25 (2.6)
Proteins (stimulance powder, pku cooler, carnosine)	3 (0.6)	4 (1.9)	3 (1.5)	10 (1.0)
Foods for enteral use (pediasure, infartini, nutrini drink, glucerna)	7 (1.3)	0 (0)	0 (0)	7 (0.7)
Herbal preparations (spirulina, jadrankin iodine)	2 (0.4)	3 (1.5)	2 (0.9)	7 (0.7)
Carbohydrates (maltodextrin, beta-glucans)	4 (0.7)	0 (0)	1 (0.5)	5 (0.5)
Amino acids (L-arginine, tryptophan)	0 (0)	3 (1.5)	0 (0)	3 (0.3)
GABA	0 (0)	1 (0.5)	2 (0.9)	3 (0.3)
Esprico	0 (0)	2 (0.9)	0 (0)	2 (0.2)
Royal jelly	1 (0.2)	1 (0.5)	0 (0)	2 (0.2)
CBD oil	0 (0)	1 (0.5)	1 (0.5)	2 (0.2)
Coenzyme q10	1 (0.2)	1 (0.5)	0 (0)	2 (0.2)
Nano zeolite	0 (0)	1 (0.5)	0 (0)	1 (0.1)
Ge132	0 (0)	0 (0)	1 (0.5)	1 (0.1)
Creatine	0 (0)	1 (0.5)	0 (0)	1 (0.1)
ALA	0 (0)	1 (0.5)	0 (0)	1 (0.1)
Noopept	0 (0)	0 (0)	1 (0.5)	1 (0.1)

In children with developmental disabilities, pain can be challenging to assess and manage due to their limited communication skills, multiple complex pain problems, and the presence of maladaptive behaviors [29]. To strengthen pediatricians' proficiency and confidence in handling this difficult issue, it is vital to provide professional education and training on the specifics of children with disabilities, including how to treat their pain [20].

Table 9 Children's physical activity

Questions	N (%)			
	Croatia	North Macedonia	Serbia	Total
Is your child involved in any type of physical activity?				
Yes	165 (46)	76 (45)	68 (40)	309 (45)
No	193 (54)	92 (55)	99 (59)	384 (55)
If yes, how many hours per week is the child involved in physical activity?				
Less than 1 h	17 (10)	19 (25)	7 (10)	43 (14)
2–3 h	69 (42)	36 (47)	37 (54)	142 (46)
4–5 h	41 (25)	16 (21)	15 (22)	72 (23)
6 h or more	38 (23)	5 (6.6)	10 (14)	53 (17)

Dietary habits

The diet of children whose parents/caregivers participated in this study is another concerning aspect. Almost half of the participants avoided certain foods for their children, even though 90% of the participants stated that their child had no diagnosed food allergy. Most parents/caregivers avoid milk and sweets for their children. The participants' reasons for avoiding certain foods were mostly non-specific, such as due to the child's underlying disease, or they considered the food unhealthy, or the child refused the food.

A casein-free diet is one of the most popular diets for children with ASD, often prescribed by pediatricians. However, there is no evidence that this diet has a meaningful effect on ASD symptoms, as any effect observed has been very small, and studies conducted on that subject thus far were of very poor methodological quality [30–32]. Similarly, our study found that the most common special diet of CDD was gluten-free. However, multiple systematic reviews have shown that there is little evidence supporting the benefits of such a diet for autism symptoms [33] and that the efficacy of gluten-free and casein-free (GFCF) diet remains unsubstantiated [30, 34]. It has also been shown that the GFCF diet might trigger gastrointestinal adverse effects [30]. All these reviews concluded that more high-quality randomized controlled trials are needed.

Children with ASD and other neurodevelopmental disorders often experience atypical sensory processing [35] that can significantly influence their food preferences and aversions. Most children with ASD exhibit hyper- or hypo-sensitivity to sensory stimuli, leading to food selectivity based on factors such as consistency, taste, smell, appearance, and temperature [36]. This sensory dysregulation can result in a preference for some types of food over others.

There is also evidence that many children with ASD often show a preference for crispy or crunchy foods, as well as salty and savory dishes. They may also be more inclined to accept foods with smooth textures, such as puréed items [37]. These foods provide a different sensory input that may be more attentive or satisfying for children with a sensory processing disorder. Salty and crunchy foods often provide a more intense and predictable sensory experience, which can benefit children who seek sensory stimulation or need to regulate their sensory input. In occupational therapy, it is often discussed that these preferences are not just a matter of taste but are closely related to the child's sensory needs. This perspective should be considered when interpreting the results related to food preferences, including the avoidance of sweets [38].

However, in this study, only 5.7% of parents reported their child's refusal of certain foods as a reason for avoiding them. This suggests that, in most cases, parents avoided certain foods primarily because they consider them unhealthy rather than due to sensory-related food aversions.

In our study, 54% of participants indicated that their children used dietary supplements. The most common answer was that the child used vitamins (77%) and probiotics (47%), with various other supplements. It has been reported in the literature that the most commonly used complementary and alternative treatments used in children with ASD are modified/special diets (for example: gluten-free, casein-free, sugar-free, lactose-free), vitamins/minerals (for example: multivitamins, vitamin B6), and food supplements (e.g., omega-3 fatty acids, dimethylglycine). Parents and caregivers may be hesitant to disclose this to their physicians because they perceive that a physician has insufficient knowledge about such interventions, that a physician could believe that such interventions are not necessary, and because a physician did not ask about their use of such interventions [39, 40].

A study of more than a thousand parents of children under age 18 years with Down syndrome from the US, Brazil, Poland, England, and the European Union indicated that 49% of participants currently/previously gave their child dietary supplement(s). On average, children took three supplements (ranging from 1 to 18), and the monthly cost of those supplements was 90 USD. Most parents indicated that they learned about supplements via friends or a parent group. Almost 20% of the participants indicated that a pediatrician of their child was not aware of the supplement use [41].

Thus, our findings align with other studies indicating that the use of dietary supplements is highly prevalent among CDDs. However, the authors warn that there is no scientific evidence about the efficacy of supplements that

CDDs are using on their symptoms or disease modification [41].

Physical activity

Based on our results, less than half of the CDD were involved in some physical activity. Among those who did have physical activity, only 17% engaged in physical activity more than 6 h per week. In 2020, Wouters et al. reported that in the Netherlands, children with moderate to severe intellectual disability had strikingly low physical fitness levels. Furthermore, disturbingly low levels of physical fitness were seen in children and adolescents with moderate to severe intellectual disabilities. Authors urged that interventions are needed to increase physical activity in this vulnerable group [42].

Relevance of the study

This study is relevant for several reasons, particularly in the context of addressing the needs of CDD in Eastern Europe, an area where there is a noted paucity of data on crucial health-related factors such as nutrition, physical activity, and pain management. The key aspects of the study's significance include addressing an understudied population in Eastern Europe, providing insights into chronic pain, dietary patterns, and physical activity in CDD, indicating implications for healthcare and policy, and providing the foundation for future research.

A critical research and literature gap is addressed by providing data on the health-related behaviors and needs of CDD in Croatia, North Macedonia, and Serbia, where such research is sparse. The study has a cultural and regional context; it sheds light on how cultural and regional factors might influence the health behaviors and challenges faced by CDD and their caregivers in these specific countries, which can differ from those in more commonly studied regions.

New insights into health issues related to CDD revealed a high prevalence of pain. This underscores the need for improved pain management and specialized training for healthcare professionals, given the challenges of assessing and managing pain due to communication barriers and complex conditions. The study also highlights the widespread use of unproven dietary interventions among caregivers, who often adopt special diets like gluten-free ones without medical or scientific support. The prevalent use of nutritional supplements that were prescribed by non-medical practitioners raises concerns about their safety and efficacy. Another key finding is the low physical activity levels among CDD patients.

The study's implications are significant for healthcare and policy, as it suggests the need for caregiver education on evidence-based practices in nutrition, physical activity, and pain management and could inform policy changes or guidelines tailored to CDD needs.

Overall, the study lays the groundwork for further research, highlighting the need for hypothesis-driven studies to explore underlying causes and test interventions to improve health outcomes of CDD.

Limitations

Our study had several limitations. Firstly, our sample was self-selected. Thus, there could be a non-response bias associated with the study findings. Participants in this study could be different from other parents/caregivers of CDD; thus, it is difficult to claim that the findings can be generalizable to all parents/caregivers of CDD in Croatia, North Macedonia, and Serbia. Furthermore, the nature of our study was descriptive, and we did not aim to conduct formal statistical comparisons between the three countries. Each variable examined in our study could be examined in more depth. Our findings can be a starting point for further studies on this topic in Eastern Europe.

Conclusion

Our findings indicate that chronic pain, inadequate dietary patterns, and insufficient physical activity are common in CDD from Croatia, Macedonia, and Serbia. By identifying these issues, the research fills a critical gap in the literature and provides actionable insights that could lead to better health outcomes for CDD through improved caregiver education and more informed healthcare practices in these regions. To improve the well-being of CDD, several actions are recommended, including enhanced education for caregivers and healthcare providers, development of culturally and regionally relevant guidelines, and increased access to support services. Further research and data collection on this topic is welcome. Future studies should aim to explore these issues in greater depth, including the long-term effects of dietary interventions, pain management strategies, and the role of physical activity in the overall development and well-being of CDD. Also, this study indicates the need for policy advocacy and implementation. Policymakers should consider these findings when designing public health initiatives and policies aimed at supporting CDD and their families. Advocacy efforts should focus on integrating these recommendations into national healthcare strategies to ensure that CDD receive the comprehensive care they need.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12887-024-05259-z.

Supplementary Material 1.

Supplementary Material 2.
Supplementary Material 3.
Supplementary Material 4.
Supplementary Material 5.
Supplementary Material 6.

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Authors' contributions
TZ, VV, DRM, MČ and LP designed the study. JM, AČ and LP analyzed the data. All authors participated in data interpretation. LP wrote the first draft of the manuscript. All authors participated in revising the manuscript for intellectual content. All authors approved final version of the manuscript.

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Data availability
Raw data collected within the study without indirect identifiers of the participants were published on Open Science Framework (available at: https://osf.io/chxyr/).

Declarations

Ethics approval and consent to participate
The study protocol was approved prospectively by the Ethics Committee of the Catholic University of Croatia Croatia on March 3, 2023 (Classification number: 641–03/23–03/045; Registration number: 498–15-06–23-002). We conducted all methods in line with the relevant guidelines and regulations. Before taking part in the study, participants received via email detailed information about the study. At the first page of the online survey interface, the participants were asked to indicate their written informed consent.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

Author details
[1]Centre for Evidence-Based Medicine and Health Care, Department of Nursing, Department of Medicine, Catholic University of Croatia, Zagreb, Croatia. [2]Institute of Emergency Medicine of Zagreb County, Velika Gorica, Croatia. [3]University Children's Hospital Medical Faculty, Skopje, North Macedonia. [4]Centre of Research Excellence in Nutrition and Metabolism, Group for Nutritional Biochemistry and Dietology, Institute for Medical Research, National Institute of Republic of Serbia, University of Belgrade, Belgrade, Serbia. [5]Cognitive Neuroscience Department, Research and Development Institute "Life Activities Advancement Centre", Belgrade, Serbia. [6]Department of Speech, Language and Hearing Sciences, Institute for Experimental Phonetics and Speech Pathology, Belgrade, Serbia. [7]Centre for Evidence-Based Medicine and Health Care, Catholic University of Croatia, Ilica 244, Zagreb 10000, Croatia.

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