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RĪGAS STRADIŅA UNIVERSITĀTE

Dace Bērtule

NEEDS OF FAMILIES WITH CHILDREN WITH CEREBRAL PALSY AND FACTORS AFFECTING THESE NEEDS

Summary of the Doctoral Thesis
for obtaining the degree of a Doctor of Medicine

Speciality – Physical and Rehabilitation Medicine

Riga, 2018

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The Doctoral Thesis is available in the RSU library and at RSU webpage: www.rsu.lv.

Secretary of the Doctoral Council:
Dr. med., Asociate Professor **Inese Gobiņa**

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ABBREVIATIONS

WHO	World Health Organization
LR	Latvian Republic
ICD-10	International Statistical Classification of Diseases and Related Health Problems 10th Revision
CSB	Central Statistical Bureau
GMFCS	The Gross Motor Function Classification Scale
CFCS	The Communication Function Classification System
FNS	The Family Needs Survey
MOPC-20	Measure of Processes of Care: MPOC-20
FSS	Family Support Scale
PSS-10	Perceived Stress Scale-10

INTRODUCTION

Cerebral palsy is the most common cause of physical disability among children with a potentially negative impact on the quality of life and involvement in the community not only for the child but also for the whole family (Johnson, 2002; Pousada et al., 2013). Meanwhile, psychic, emotional and financial welfare of the child's closest relatives is a significant factor promoting the child's development. (Murphy et al., 2011; Rosenbaum, 2011). Therefore, health care providers should be aware that, in order to promote successful child's development, such kind of service is needed that simultaneously targets improvement of the functions of the child and his family.

Services based on the principles of family-centred care have been recognized as the most efficient services in the work with families with children who have developmental disorders (King et al., 2004; Kuhlthau et al., 2011). There have been findings that in this way the best results can be achieved in improving the child's functioning and meeting the family's specific needs, as well as increasing the quality of life (Kuhlthau et al., 2011; Law et al., 2003; Dempsey & Keen, 2008; Dunst & Trivette, 2009; Darrah et al., 2012; Kuo et al., 2011; Almasri et al., 2011; Almasri et al., 2014). Family-centred services are such type of services where the opinion of the child's relatives is heard and respected, families are involved in decision making, the child's treatment or rehabilitation process, and every family member receives the necessary support (Rosenbaum, 2011). Still, family-centred service is a challenge for health care specialists (Espe-Sherwindt, 2008; Jeglinsky et al., 2012). Health care specialists admit that they lack competence to solve matters that are not directly related with the child's medical condition, and they note that not always they are informed about the family's wishes and needs (Jeglinsky et al., 2012).

A significant aspect of family-centred health care is study of family needs and priorities (Bamm & Rosenbaum, 2008; Dunst & Dempsey, 2007). Meanwhile, information about factors influencing family needs would help to understand the potential needs of each individual family, thus, offering the support that is most important for the particular family.

Based on the ecological theory of family systems and human development, the factors affecting potential family needs are determined by features and characteristics of every individual in the family, the family as a whole and the environment (Broderick, 1993). Therefore, information about the characteristics of the child, the family, services that can possibly influence the family needs would promote provision of family-centred services to families with a child having cerebral palsy, thus, providing the best possible support for the child's development and improvement of the quality of life for the family.

The aim of the study

To identify and describe needs of the families with preschool children with cerebral palsy, and to study how these needs relate with the factors characterising families, children and rehabilitation services.

The objectives of the study

1. To identify the specific needs of the families with preschool children with cerebral palsy;
2. To assess and analyse correlation between the needs of the families with children with cerebral palsy and:
   - the factors characterising the demographic and socio-economic situation of the families,
   - the factors characterising children with cerebral palsy,

- the factors characterising availability of rehabilitation services and cooperation between the family and rehabilitation service providers.

3. To assess the impact of factors characterising families, children and rehabilitation services on the needs of the families with children with cerebral palsy.

Hypothesis of the study

Needs of families raising preschool children with cerebral palsy living in Latvia are affected by factors characterising families, children with cerebral palsy and rehabilitation service providers, and the unique impact of these factors depends on the type of family needs.

Scientific novelty of the study

This is the first time the needs of families with children with cerebral palsy have been studied in Latvia. The study reveals the specific needs of the families raising preschool children with cerebral palsy living in Latvia. A comprehensive and systematic approach to understand and identify the factors affecting family needs has been used in the study. The results obtained during the study ensure understanding of the models of specific family needs and the influencing factors, thus, promoting awareness of the health care service providers about the potential needs of families with preschool children with cerebral palsy and the factors influencing those needs.

The information obtained during the study will help health care service providers to assess, understand and predict the specific needs of the family, ensuring development and implementation of a service plan based on the family needs, thus, improving the quality of the service, promoting the quality of life of the families raising children with cerebral palsy and inclusion of those families in the society.

1. MATERIAL AND METHODS

1.1. Model of the Determinants of Family Needs

Conceptual model of the determinants of family needs (Fig.1.1) was developed based on:

- the ecological theory of family systems and human development, determining that family needs can be influenced by peculiarities of the individual, the whole family and the surrounding environment (Broderick, 1993);
- comprehensive study of literature, collecting information about types of needs of families raising children with cerebral palsy and identifying the possible factors affecting these family needs.

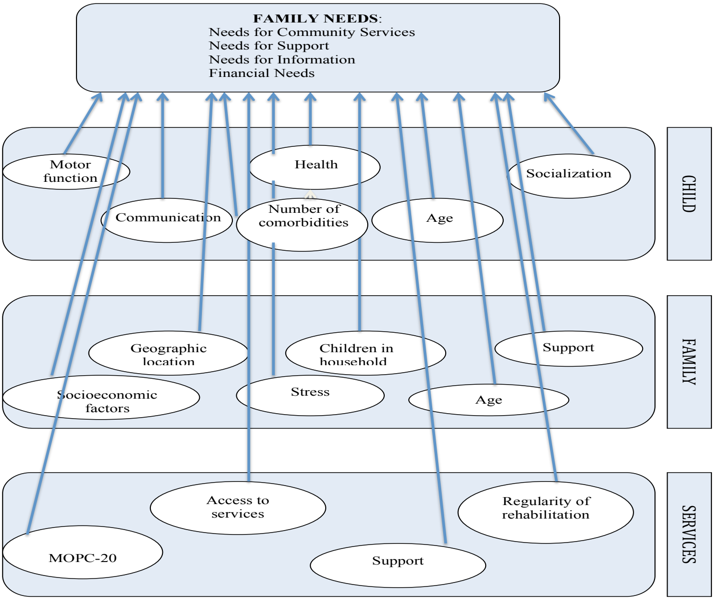

Fig.1.2. **Model of the Determinants of Family Needs**

1.2. Study subjects

The study covered 234 families living in Latvia who, during the time period of collecting data for the study from March 1, 2012, until June 1, 2013, had a child diagnosed with cerebral palsy and met the criteria for the study.

Criteria for the study:

- the child's main clinical diagnosis: cerebral palsy (according to ICD-10 classification: G80);
- the child's age is 2–7 years (born in 2004–2010);
- the family's permanent place of residence in the Republic of Latvia;
- the child's primary caretaker has agreed to participate in the study.

Families were not included in the study if any of the exclusion criteria could be applied:

- the child's primary clinical diagnosis is other neuromuscular disorder than cerebral palsy;
- the child with cerebral palsy has additional disorders that might seriously affect the quality of life of the child and the family (e.g. severe autism spectrum disorder, cystic fibrosis, malignant tumour);
- any of the family members has severe health disorders that might affect the quality of life of the child and the family (e.g. progressing neuromuscular disorder, severe autism spectrum disorder, cystic fibrosis, malignant tumour, severe mental retardation);
- in the past two years the family has not used services of the state of local government (e.g. medical or social rehabilitation, preschool educational institutions, daycare centre) for the child with cerebral palsy.

1.3. Study procedure

The authors of the study aimed to address all families living in Latvia who are raising a preschool child, aged 2–7, diagnosed with cerebral palsy. Information about the number of children with cerebral palsy registered in Latvia was obtained from the State Medical Commission for the Assessment of Health Condition and Working Ability. According to the data, 264 children with the status of disability assigned based on ICD code G80 (cerebral palsy) and who were born in 2004–2010 were registered. Contact information of the families was obtained through patients' register and medical documentation of the Children's Clinical University Hospital, National Rehabilitation Centre "Vaivari" and "Mēs esam līdzās" organisation. If during the selection process the families visited any of the above – mentioned institutions, they were addressed. If the family met the criteria and agreed to participate in the study, a functional assessment of the child was conducted, and the child's primary caretaker filled in the questionnaires included in the assessment methods. If the family did not visit any of the above – mentioned institutions, the family was addressed by telephone, informed about the study and a meeting was arranged if the family agreed to participate. In most of the cases, a period was selected when the child had an ongoing rehabilitation course in any of the above-mentioned institutions. Seven families were visited at the place of their residence.

The selection and assessment of the participants was conducted in a time period from March 1, 2012, until June 1, 2013. Assessment of the child's functions and questionnaires took 90 minutes on average. The author of the study was present to answer any questions that may arise during filling of the questionnaire. Some respondents chose to take their time to fill in the questionnaires and returned them the following day.

The obtained data were processed using statistical data processing and analysis methods.

As standardised self-evaluation questionnaires were used in the study as an assessment method, and the originals of the questionnaires are in English and had not been translated into Latvian before the study, the questionnaires were translated in line with the recommendations of the World Health Organization (WHO, Process of translation and adaptation of instruments), and a pilot study was conducted to test reliability of the Latvian translation of the questionnaire. 20 random parents who were members of organisation "For Latvian Children with Disabilities" and who had preschool children with non-progressing neurological disorders were involved in the pilot study. Parents filled in the questionnaires in the Latvian language two times (with 7–14 days interval in between). In order to assess reliability of the Latvian questionnaire, assessment of the consistency of the scale (*Cronbach alpha* analysis) was conducted and *Intraclass Correlation Coefficient* was tested.

1.4. Study tools (methods)

Outcome Measure

The Family Needs Survey (FNS)

In order to identify family needs, the child's primary caretaker filled in the Family Needs Survey – a modified questionnaire of the Family Needs Survey developed by Bailey and Simeonsson. The scale has been developed in order to study needs of the families raising preschool children with development disorders (Bailey & Simeonsson, 1988). The Family Needs Survey has respective reliability indicators. The internal consistency (Cronbach alpha*)* ranges from 0.65 to 0.86 (Sexton, 1995), test-retest reliability, filling in the questionnaire with a six-month interval is r = 0.81 if the respondent is the father of the child, and r = 0.67 if the respondent is the mother of the child. (Bailey & Simeonsson, 1988).

Originally the survey consists of 35-items. Items are grouped in 6 subscales according to the type of needs: 1) Needs for Information; 2) Needs for Support; 3) Explaining to Others; 4) Community Services; 5) Financial Needs; 6) Family Functioning. In order to study needs of those families whose children are over the preschool age, Palisano and his colleagues also added several statements to the questionnaire (Palisano et al., 2010).

With the permission of the authors, the original questionnaire was used in the present study and three questions and three statements recommended by Palisano and colleagues were added to it, allowing to identify needs related with availability and coordination of services.

The internal consistency (Cronbach alpha) and test-retest reliability (ICC 2.1) of the translated and modified version of FNS were tested in advance of the original study. The Cronbach alpha coefficient for all items was 0.82 and ranged between 0.71 and 0.89 for each subscale. ICC 2.1 for all items was 0.89 and the coefficient varied from 0.72 to 0.98 (Bērtule & Vētra, 2012).

The items are rated on a 3-point scale. The response options are: 1 = I definitely do not need help with this, 2 = Not sure, 3 = I definitely need help with this. For the purpose of this study, only the items that were scored with number 3 (I definitely need help with this) were considered to be unmet family needs and were scored for getting the total number of family needs and the number of each type of need for data analysis.

As two of the areas of needs (need for support and need for family functioning) are related with the wish for support, then, like Almasri's study, they were considered as a single bloc of needs – the need for support. (Almasri, O'Neil & Palisano, 2014).

Determinants Measures

Questionnaire for general information

Authors of the study developed a questionnaire to obtain information about the age and education of the child's primary caretaker, the family structure, socio-economic situation, the place of residence, the child's overall health condition, as well as availability of rehabilitation services in the place of residence and the regularity of the service provision.

Measure of Processes of Care: MPOC-20

The Measure of Processes of Care (MPCO-20) is a 20-item self-report about parental perception about the extent to which the health services that they and their child receive are family-centred. The survey includes five subscales:

- Enabling and Partnership
- Providing General Information
- Providing Specific Information
- Co-ordinated and Comprehensive Care
- Respectful and Supportive Care

The items are rated on the Likert scale, ranging from 1 to 7 (1 = the described event or situation was not perceived; 7 = the described event or situation was perceived to a very great extent) (King et al., 2004).

This study made use of a version of the MPOC-20 that was translated into Latvian. Internal consistency (Cronbach's alpha) and test-retest reliability (ICC 2,1) of the translated version of the MOPC-20 were tested before the original study. The Cronbach's alpha co-efficient for all 20 items was 0.87 and varied between 0.77 and 0.94 for each subscale. The ICC 2,1 for all items was

0.94, and the co-efficient varied between 0.93 and 0.96 (Bērtule & Vētra, 2012).

Family Support Scale (FSS)

The Family Support Scale (FSS) consists of 18 questions, and respondents rate to what extent the persons or organizations named in the question have helped or provided support. The questions are grouped in order to provide information to what extent the child's primary caretaker received support and assistance from:

- other family members – Support from Family;
- friends – Support from Friends;
- colleagues, social groups – Informal Support;
- therapists, teachers etc. – Formal support.

The questions are answered on a Likert scale, and possible answers are: 5 – helps very much, 4 – helps quite much, 3 – usually helps, 2 – sometimes helps, 1 – does not help at all. A higher score suggests of a larger support and assistance. The Family Support Scale is standardized and it has high reliability and validity indicators for the clinical studies (Dunst, Jenkins & Trivette, 1984).

The study used the Latvian version of the scale. In the pilot study conducted before the main study, the Latvian translation of the FSS had adequate internal consistency (*Cronbach alpha* = 0.81) and test-retest reliability (*ICC* = 0.91). In the present study, describing the support the child's primary caretaker received, we distinguished three types of support:

- Support from Family;
- Informal Support (combining support from friends and social groups);
- Formal support.

Perceived Stress Scale-10

The Perceived Stress Scale (PSS) measures to what extend an individual has felt stressful situations in the past month. The scale includes 10 positive and negative statements which have to be answered on a Likert scale. The possible answers are: 5 – very often, 4 – quite often, 3 – sometimes, 2 – almost never, 1 – never. In order to obtain the overall stress perception indicator, the positive statements received a reversed score (i.e. if a question is scored with “5”, the score turns into “1”, etc.), then all scores are added up, and the total perceived stress indicator is obtained. The higher the indicator, the higher the perceived stress level.

The Perceived Stress Scale is widely used in psychology, sociology and health care studies, the scale is standardized, its reliability and validity has been tested on individuals of different ages. (Cohen, Kamarck & Mermelstein, 1983).

The study used the Latvian translation of the scale by Ieva Stokenberga for her Doctoral Thesis “The Role of Humour in the Process of Overcoming Stress” with the permission of the author and the Psychology Department of the University of Latvia. The internal consistency of the Latvian translation of the Perceived Stress Scale was *Cronbach alpha* = 0.83 (Stokenberga, 2008).

The Gross Motor Function Classification Scale (GMFCS)

GMFCS is a five-level classification system used to describe gross motor function for children with cerebral palsy. The scale is standardized and clinically approbated for use of describing motor functions for children of the age of 1–18 (Palisano et al., 1997). Assessment and classification of motor functions are conducted in line with the age groups. A description of assessment of motor functions for five age groups has been developed: up to 2 years of age, 2–4 years, 4–6 years, 6–12 years, 12–18 years. The assessment is conducted while observing the child's abilities while sitting, changing positions and moving, and the performance determines which GMFCS level corresponds the child's motor functions. Children with motor functions at GMFCS I level can perform almost the same functions as other peers with the only difference being the speed of the performance, balance or coordination. Children with motor functions at GMFCS V level cannot control the position of their head and body, conduct purposeful movements, move themselves around. GMFCS as a measure of child's mobility is widely used in everyday clinical work and research because it provides structured information about the level of mobility limitations of the participants of the study (Rethlefsen et al., 2010). A short description of GMFCS levels is included in table 1.1.

Table 1.1

The level description of Gross Motor Function Classification System (GMFCS)

Level	Description
I	Walks without limitation
II	Walks with limitation
III	Walks with assistive mobility devices
IV	Self–mobility with limitation, children are transported or use wheeled mobility
V	Self–mobility is severely limited, children are transported

Assessment of the child's motor functions was conducted, observing the child during a physiotherapy session in the therapy premises or other premises of the building (for example, to assess mobility on stairs), consulting the child's physiotherapist and caretaker in case of unclarity. If the family was visited at their place of residence, the assessment was conducted there.

The Communication Function Classification System (CFCS)

CFCS developed by Hidecker and colleagues is a five-level classification system characterising communication performance that initially was developed for use with children with cerebral palsy (Hidecker et al., 2011), but recently it has been approved for use also in other cases with children who have communication disorders (Hidecker et al., 2017). The scale can be used to describe communication performance for children starting from the age of two. The classification principle is similar to that of GMFCS – children at CFCS I level are able to communicate at the same level as their peers without any communication disorders, while children at CFCS V level are not able to communicate efficiently. In order to determine which CFCS level the child's communication performance corresponds, the child's communication with the relatives as well as unfamiliar people was observed. The child's ability to receive and send information irrespective of the way it is being done was assessed. The child may use language, eye contact, gestures, communication devices, etc. for communication. CFCS levels are described in table 1.2.

Table 1.2

The level description of Communication Function Classification System (CFCS)

Level	Description
I	Sends and receives information with familiar and unfamiliar partner effectively
II	Sends and receives information with familiar and unfamiliar partner – may need extra time
III	Sends and receives information with familiar partner but not with unfamiliar partners
IV	Inconsistently effectively sends and receives information even with familiar partner
V	Seldom effectively sends and receives information even with familiar partner

Assessment of the child's communication performance was conducted, observing the child's communication with physiotherapist, occupational therapist or speech therapist during the therapy and engaging in communication with the author which was unfamiliar to the child. Communication with relatives was observed, and the caretaker's assessment on the child's communication skills was noted. The respective CFCS level was selected at once if the assessment of the author and the caretaker matched. If the opinions differed, a speech therapist who was familiar with the child was engaged.

The data used in the study analysis and their description are presented in table 1.3.

Table 1.3

Data used in study analysis and their description

Variable	Measures used to obtain data, type of data
OUTCOME MEASURES	
Family Needs (overall)	FNS: items 0–41
Needs for Information	FNS: items 0–9
Needs for Support	FNS: items 0–13
Financial Needs	FNS: items 0–7
Needs for Community Services	FNS: items 0–6
INDEPENDENT VARIABLES ***Child variables***	
Age	Questionnaire; years
Motor function	GMFCS: items 1–5
Communication function	CFCS: items 1–5
Comorbidities (total number)	Questionnaire: number of comorbidities 0–6
Child's health (parent reported)	Questionnaire: rather good/rather poor
Socialization	Questionnaire: pre-school/ no pre-school
Family variables	
Age	Questionnaire: years
Employment	Questionnaire: employed/ not employed
Education	Questionnaire: Lower than secondary school/ Secondary school/ Bachelor's or Master's degree
Marital status	Questionnaire: Married or living with partner/ Single

Table 1.3 continued

Family income level (self report)	Questionnaire: high / average/ low
Children in household	Questionnaire: one/ two or more
Geographic location	Questionnaire: Riga/ Urban/ Rural
Stress	PSS-10: items 10–50
Family support	FSS: items 6–30
Informal support	FSS: score 7–35
Service variables	
Formal support	FSS: score 5–25
Access to rehabilitation services	Questionnaire: yes/no
Regularity of rehabilitation	Questionnaire: regularly/ at least twice a year/ once a year
Family-centredness of services	
Enabling and Partnership	MOPC-20: items 3–21
Providing General Information	MOPC-20: items 5–35
Providing Specific Information	MOPC-20: items 3–21
Co-ordinated and Comprehensive Care	MOPC-20: items 4–28
Respectful and Supportive Care	MOPC-20: items 5–35

1.5. Statistical methods of the study

The descriptive statistical methods were used for data analysis (average values, standard deviation, minimum and maximum values), and frequency of occurrence of particular data was analysed. Distribution of data was tested using histograms.

In order to study reliability and distinctiveness of impact of different factors on one model (family needs) that consists of several latent variables, multiple linear regression analysis was conducted, performing the following steps:

- dependent variables and independent quantitative variables were tested for normal distribution. If the dependent variable did not meet the normal distribution requirements, it was logarithmically scaled;
- in order to discover whether there is correlation between the dependent and independent variable, depending on the type of the analysed data and

compliance with normal distribution, Pearson or Spearman correlation analysis was conducted. Only those independent variables that statistically reliably ($p < 0,05$) correlated with the dependent variable were included in the regression analysis;

- if the independent variable was nominal with several categories, it was recoded in dummy variables;
- multiple linear regression analysis was conducted, including the selected independent variables. *Enter* method was used for regression analysis, but *Forward* and *Backward* methods were used to compare the results;
- the best model was selected, comparing them with F test. If two models differed considerably ($p < 0,05$), the model with higher R^2 was selected. If the models did not differ substantially, the model with a lower number of explanatory variables was selected;
- every end-model that explained the result best was tested for colinearity, linearity and normal distribution requirements;
- factors that were included in the final model and were statistically significant were one by one excluded from the model and the obtained R^2 changes were used in describing the factors' unique contributions to the model.

IBM SPSS 17 software was used for data processing.

2. RESULTS

2.1. Participants of the research

As many as 259 children, aged 2–7, with G80 diagnosis were identified in the archives and databases of National Rehabilitation Centre "Vaivari", the Children's Clinical University Hospital, and organisation "Mēs esam līdzās". The author was not able to establish contacts with five families, representatives of 18 families refused to participate in the study, in two cases one of the exclusion criteria was applied, therefore 234 families were engaged in the study: a child with cerebral palsy and the child's primary caretaker.

In the majority of cases (93.2%) the family was represented and questionnaires were filled by the child's mother. The average age of respondents was 35.0 (SD = 8.9 years). The majority of respondents (82.1%) were married or living with a permanent partner. Half of the respondents were not employed during the time when the data were obtained. A detailed characteristics of respondents and families is described in table 2.1.

Table 2.1

Characteristics of participants and their families

Characteristics	n	%	95% CI
Relationship to the child			
Mother	218	93.2	89.9–96.4
Father	4	1.7	0.5–3.3
Grandmother	8	3.4	1.1–5.7
Guardian	4	1.7	0.5–3.3
Education			
Bachelor's/Master's degree	92	39.3	33–45.6
Secondary school	122	52.2	45.6–58.6
Lower than secondary school	20	8.5	4.9–12.1
Employment			
Employed	117	50	43.6–56.5
Not employed	117	50	43.6–56.5

Table 2.1. continued

Marital status			
Married or living with partner	192	82.1	77.1–87
Single	42	17.9	13–22.9
Children in household			
One	115	49.1	42.7–55.6
Two or more	119	50.9	44.8–56.1
Geographic location			
Rīga	84	35.9	29.7–42.1
Urban (any other city)	89	38.0	31.7–44.3
Rural	61	26.1	20.4–31.7
Family income (EUR per month)			
Less than 420	42	18.0	13.9–23.9
420 – 839	136	58.1	49.2–63.1
840 – 1120	39	16,6	10.1–21.9
More than 1120	17	7.3	3.9–12.7
Family income level*			
Low	44	18.8	14.1–24.2
Average	157	67.1	61.1–73
High	33	14.1	9.6–18.6

*Parent – reported

The Perceived Stress Scale (PSS) of respondents varied from 6 points to 42 points, with 24.4 points on average (SD = 7.1 points).

Assessment of support provided to respondents by family members (FSS family) was in the range between 5 points and 22 points with 12.5 point on average (SD = 3.5 points), while assessment of support from friends and social groups (FSS informal) varied from 8 points to 26 points, with 18.8 points on average (SD = 3.5 points). The assessment of support provided by professionals (FSS professionals) ranged from 4 points to 15 points with 8.8 points on average (SD = 2.5 points).

The average age of children with cerebral palsy was 4.8 years (SD = 1.7). The majority of children (79.9%) has the type of spastic cerebral palsy.

In addition to mobility disorders, 78.6 percent of children had at least one comorbidity. The total number of comorbidities ranged from 0 to 5 with 2.5 comorbidities on average (SD = 1.4). A detailed description of children with cerebral palsy is given in table 2.2.

Table 2.2

Characteristics of the children with cerebral palsy

Characteristics	n	%	95% CI
Gender			
Male	131	55.6	49.1–61.9
Female	105	44.4	38–50.8
Comorbidities*			
Visual impairment	93	39.7	33,.4–45.9
Hearing impairment	28	12.0	7.8–16.1
Cognitive impairment	158	67.5	61.5–73.5
Behaviour disturbance	24	9.7	6.8–12.2
Seizure	58	24.8	19.3–29.9
Child health*			
Rather good	94	39.7	36.2–43.1
Rather poor	142	60.3	56.1–64.8
Socialization			
Yes (pre – school etc.)	140	59.4	53.1–65.2
No (home)	96	40.6	36.2–44.3
Type of cerebral palsy			
Spastic unilateral	77	32.9	26.8–28.9
Spastic bilateral	112	47	40.5–53.4
Dyskinetic	25	10.7	6.7–14.6
Ataxic	9	3.8	1.4 - 6.3
Not specified /mixed	13	5.6	2.6–8.5
GMFCS level			
I	78	33.3	27.3–39.1
II	45	19.2	14.7–23.8
III	44	18.1	14.4–21.7
IV	49	20.9	16.7–25.1
V	20	8.5	5.1–11.9
CFCS level			
I	55	23.5	19.3–27.8
II	42	17.9	13.5–21.9
III	45	18.4	14.3–22.3
IV	56	23.9	19.4–28.4
V	38	16.2	12.4–20

*Parent – reported

2.2. Description of availability and regularity of rehabilitation services

As many as 149 respondents or 63.7 percent (95% CI: 58.7–68.1) said that they have rehabilitation services available at the place of residence, while 85 respondents or 36.3% (95% CI: 32.1–39.8) said that there are no appropriate rehabilitation service available close to their place of residence.

Analysing regularity of rehabilitation, the authors discovered that 60 children or 25.6% (95% CI: 20–31.2) receive government-funded rehabilitation services on a regular basis, 93 children or 39.7% (95% CI: 33.4–46.1) undergo rehabilitation in courses several times a year, and 81 children or 34.6% (95% CI: 28.4–40.7) undergo rehabilitation course once a year or less frequently.

2.3. The results of Measure of Processes of Care (MOPC-20)

Analysis of results of the Measure of Processes of Care (MOPC-20) revealed that rehabilitation service providers partly follow principles of family-centred services. Respondents were most positive about such principles as "Respectful and Supportive Care" (mean = 4.84; SD = 1.8), "Enabling and Partnership " (mean = 4.65; SD = 1.29) and "Co-ordinated and Comprehensive Care" (mean = 4.62; SD = 1,17). Respondents were more negative about principles related with provision of information – "Providing Specific Information" (mean = 3.62; SD = 1.21) and "Providing General Information" (mean = 3.32; SD = 1.20).

2.4. The results of Family Needs Survey (FNS)

Analysing the overall results of the Family Needs Survey, the authors discovered that every respondent marked at least three statements regarding the needed assistance.

The largest number of needs was marked in the subscale "Needs for Information". In this section, respondents less often (53.4%) noted that they need information about the child's development and how to play with the child, but more often (88.9%) they marked the necessity for information about the available services.

In the subscale "Needs for Support", responding to eight statements of this FNS section, respondents most often marked the wish to read about families with similar problems (72.2%), while just 19.2% of respondents said that they would need a family member to talk about his/her own problems.

In the subscale "Community Services", most of respondents (72.6%) marked the need to receive support in coordination of the state or municipal medical, social and education services. Just three respondents noted that they would need assistance and care for the child during a church service.

In the subscale "Financial Needs", most of respondents said that they would need financial support to cover medical treatment of their child (76.9%) and purchase special equipment (57.3%). At the same time, just 10% of respondents said that the family needs financial support to buy toys for the child.

Just a small share of respondents marked needs related with improvement of family functioning ("Family Functioning" subscale) or that they would need help to explain the condition of their child to other people ("Explaining to Others" subscale). Detailed information about the Family Needs Survey is available on table 2.3.

Table 2.3

The results of Family Needs Survey

Need	n*	%
Needs for Information		
I need more information about how children grow and develop	125	53.4
I need more information about my child's condition or disability	157	67.1
I need more information about how to play or talk to my child	125	53.4
I need more information about how to teach my child	178	76.1
I need more information about how to handle my child's behaviour	143	61.1
I need more information on the services that are presently available for my child	208	88.9
I need more information about the services that my child might receive in the future	199	85.0
I need more information about planning for my child's future well-being)	167	71.4
I need help in finding information about future education for my child	200	85.5
Needs for Support		
I need to have someone in my family that I can talk to more about problems	45	19.2
I need to have more friends that I can talk to	63	26.9
I need to have more opportunities to meet and talk with parents of children who have disabilities	137	58.5
I need reading material about other parents who have a child similar to mine	169	72.2
I need to have more time for myself	149	63.7
I need to have more time just to talk with my child's teacher or therapist	105	44.9
I need to talk more to minister who could help me deal with problems	51	21.8
I would like to meet more regularly with a counsellor(psychologist, social worker, psychiatrist) to talk about problems	105	44.9
Explaining to Others		
I need more help in explaining my child's condition to either my parents or my spouse's parents	34	14.5
I need more help in explaining my child's condition to my spouse	21	9.0
I need more help in how to explain my child's condition to his/her siblings	19	8.1
I need help in explaining my child's condition to other children	78	33.3
I need help in knowing how to respond when friends, neighbours, or strangers ask questions about my child's condition	79	33.8
I need help in explaining my child's condition to teachers and other professionals	68	29.1
Community Services		
I need help in locating a child care centre or pre-school for my child	108	46.5

Table 2.3. continued

I need help locating babysitters or respite care providers who are willing and able to care for my child	74	31.6
I need help in getting appropriate care for my child in our church or synagogue during services	3	1.3
I need help locating a doctor who understands me and my child’s needs	80	34.2
I need help in locating rehabilitation services for my child	143	61.1
I need help in coordinating medical, developmental, educational, and other community services for my child	170	72.6
Financial Needs		
I need more help in paying for expenses such as food, housing, medical care, clothing, or transportation	92	39.3
I need more help in paying for special equipment that my child needs	134	57.3
I need more help in paying for therapy, child care, or other services that my child needs	180	76.9
I need more help in paying for babysitting or respite care	82	35.0
I need more help in paying for home modifications	68	29.1
I need more help in paying for toys that my child needs	24	10.3
I or my spouse need more counselling or help in getting a job	45	19.2
Family Functioning		
My spouse needs help in understanding and accepting our child’s condition	12	5.1
Our family needs help in discussing problems and reaching solutions	40	17.1
Our family needs help in learning how to support each other during difficult times	61	26.1
Our family needs help in deciding who will do household chores, child care, and other family tasks	3	1.3
Our family needs help in deciding and doing recreational activities	39	16.7

*Number of respondents with mark "3" (I definitely need help with this)

The average number of needs marked by respondents was 17.1 (SD = 7.1), varying from 3 to 38. The score value characterising respondent needs in separate types of needs can be seen in table 2.4.

Table 2.4

The results for subscales of Family Needs Survey

Subscale	Items in subscale	Min	Max	Mean	SD
Needs for Information	9	0	9	6.5	2.0
Needs for Support	8	0	8	3.5	2.1
Explaining to Others	6	0	6	1.3	1.5
Community Services	6	0	6	2.5	1.3
Financial Needs	7	0	7	2.7	1.4
Family Functioning	5	0	5	0.7	0.9

For further analysis two types of needs ("Needs for Support" and "Family Functioning") were viewed together, forming "Needs for Support" where the average number of needs was 4.3 (SD=2.1), varying from 0 to 10.

As the number of needs in the subscale "Explaining to Others" was small, the influencing factors were not viewed for this type of needs.

2.5. Results of correlation analysis

In order to determine correlation between the needs of families of children with cerebral palsy and the influencing factors, depending on the type of the analysed data, Pearson's or Spearman's correlation analysis was conducted.

2.5.1 Correlation between family needs and child's characteristics

The age of the child was not related with family needs. Other factors characterising children with cerebral palsy were related with at least one type of family needs. Correlations that were statistically significant are depicted in table 2.5.

Table 2.5

Statistically significant correlations between family needs and child's characteristics

	Needs for Information	Needs for Support	Community Services	Financial Needs	Family Needs (total)
Age	-	-	-	-	-
GMFCS level	0.10*	0.17*	0.45	0.44	0.34
CFCS level	0.34	0.24	0.46	0.37	0.42
Socialisation	0.16*	0.22	0.42	0.26	0.31
Child health	0.15*	-	-	-	0.19*
Number of comorbidities	0.28	0.36	0.37	0.36	0.46

$p < 0.001$
*$p < 0.05$

2.5.2. Correlations between family needs and family characteristics

No statistically significant correlation was found between family needs and the age and family status of the child's primary caretaker. Other factors characterising the family were related with at least one type of family needs. Correlations that were statistically significant are depicted in table 2.6.

Table 2.6

Statistically significant correlations between family needs and family characteristics

	Needs for Information	Needs for Support	Community Services	Financial Needs	Family Needs (total)
Age	-	-	-	-	-
Marital status	-	-	-	-	-
Education	0.16*	0.19*	-	-	0.20*
Employment	0.21	0.19*	0.33	0.35	0.34
Family income level	0.31	0.29	0.36	0.46	0.43
Geographic location	-	-	0.19*	-	-

Table 2.6 continued

Children in household	-	-	-	0.15*	-
Stress	0.22	0.30	0.15*	0.22*	0.33
Support from Family	−0.23	−0.44	−0.18*	−0.27	−0.39
Informal support	−0.28	−0.26	−0.13*	−0.19*	−0.31

$p < 0.001$
$^*p < 0.05$

2.5.3. Correlations between family needs and service characteristics

Correlations analysis revealed that all factors characterising rehabilitation services are related with at least one type of family needs. Correlations that were statistically significant are depicted in table 2.7.

Table 2.7

Statistically significant correlations between family needs and service characteristics

	Needs for Information	Needs for Support	Community Services	Financial Needs	Family Needs (total)
Respectful and Supportive Care	−0.19*	−0.23	−0.30	−0.27	−0.30
Enabling and Partnership	−0.28	−0.35	−0.32	−0.36	−0.40
Co-ordinated and Comprehensive Care	−0.22	−0.25	−0.29	−0.25	−0.31
Providing General Information	−0.20*	−0.17*	−0.18*	−0.21	−0.25
Providing Specific Information	−0.14*	-	−0.21*	−0.14*	−0.16*
Formal support	−0.34	−0.35	−0.29	−0.29	−0.43
Regularity of rehabilitation	-	-	0.19*	0.13*	-
Access to rehabilitation services	-	-	0.14*	0.14*	-

$p < 0.001$
$^*p < 0.05$

2.6. Results of multiple linear regression analysis

In order to explain factors influencing family needs, multiple linear regression analysis was used. Five family needs models were distinguished and viewed for the analysis:

- the model that explains overall family needs;
- the model that explains family needs for support;
- the model that explains family needs for community services;
- the model that explains financial needs of the family;
- the model that explains family needs for information.

All final models met the requirements of colinearity, linearity and normal distribution of the regression analysis.

2.6.1. Model that explains overall family needs

The total number of needs (FNS) marked by families was used as the dependent variable. In the initial model five factors characterising children with cerebral palsy (GMFCS level, CFCS level, socialisation, overall health condition, the number of comorbidities), six factors characterising families (respondent's education level, employment, family income level, the perceived stress level of the child's primary caretaker, family and informal support), and six factors characterising rehabilitation services (five MOPC subscales and professional support) were used as independent variables.

The final model with nine independent variables explained 61% (adjusted $R^2 = 0.61$) of the variance of overall family needs. The final model and the unique influence of each independent variable that had a statistically significant impact on the total number of family needs are presented in table 2.8.

Table 2.8

Multiple regression model explaining overall family needs

Regression model: **F(9, 233) = 39.18; p = 0.000**						
Variable	B	SE	β	t	p	% of unique contribution
Income level						2.3
low vs high	4.23	1.14	,24	3.882	0.000	
average vs high	1.96	0.88	,13	2.355	0.032	
Employed vs not employed	2.52	0.63	,19	4.151	0.000	2.8
Support from Family	−0.58	0.08	−,39	−6.835	0.000	8.2
Stress	0.18	0.04	,18	4.245	0.000	3.0
GMFCS Level	0.51	0.22	,11	2.261	0.040	0.7
Number of comorbidities	0.85	0.22	,19	3.932	0.000	2.5
Enabling and Partnership	−1.18	0.25	−,22	−4.872	0.000	3.9
Formal support	−0.56	0.12	−,21	−4.556	0.000	3.5

2.6.2. Model that explains family needs for support

The number of needs for support marked by families (total number of needs in subscales "Needs for Support" and "Family Functioning" in FNS) was used as the dependent variable in this model. Four factors characterising children with cerebral palsy (GMFCS level, CFCS level, socialisation, the number of comorbidities), six factors characterising families (respondent’s education level, employment, family income level, the perceived stress level of the child’s primary caretaker, family and informal support), and five factors characterising rehabilitation services (four MOPC subscales and professional support) were used as independent variables in the initial model.

The final model explained 44% of the variance (adjusted $R^2 = 0.44$). The final model and the unique contribution of each independent variable that had a statistically significant impact on the total number of family needs for support are depicted in table 2.9.

Table 2.9

Multiple regression model explaining family needs for support

Regression model: **F(7, 233) = 26.65; p = 0.000**						
Variable	B	SE	β	t	p	% of unique contribution
Education						2.1
Lower than secondary school vs Secondary school	1.29	0.49	,13	2.568	0.011	
Bachelor's or Master's degree vs Secondary school	0.21	0.14	,04	0.715	0.475	
Stress	0.06	0.02	,16	3.164	0.002	2.7
Enabling and Partnership	−0.46	0.11	−,22	−4.126	0.000	4.5
Support from Family	−0.28	0.03	−,37	−7.422	0.000	13.9
Formal support	−0.23	0.05	−,21	−4.011	0.000	4.2
Number of comorbidities	0.34	0.09	,19	3.603	0.000	3.5

2.6.3. Model that explains family needs for community services

The number of family needs for community services ("Community Services" subscale in FNS) was used as the dependent variable in this model. Five factors characterising children with cerebral palsy (GMFCS level, CFCS level, socialisation, overall health condition, the number of comorbidities), six factors characterising families (respondent's education level, employment, family income level, the perceived stress level of the child's primary caretaker, family and informal support), and eight factors characterising rehabilitation services (five MOPC subscales, access to rehabilitation services in the place of residence, the regularity of receiving the rehabilitation services and professional support) were used as independent variables in the initial model.

The final model explained 52% (adjusted $R^2 = 0.52$) of the variance of family needs for community services. The end-model and the unique influence of each independent variable that had a statistically significant impact on the total number of family needs for community services are depicted in table 2.10.

Table 2.10

Multiple regression model explaining family needs for community services

Regression model: **F(8,233) = 32.23; p = 0,000**						
Variable	B	SE	β	t	p	% of unique contribution
CFCS level	0.32	0.06	,28	5.341	0.000	5.8
Pre-school vs no pre-school	0.72	0.17	,25	4.244	0.000	3.7
Income level						2.2
low vs high	0.98	0.28	,23	3.375	0.002	
average vs high	0.45	0.21	,13	1.958	0.051	
Employed vs not employed	0.48	0.16	,17	3.112	0.007	1.7
Stress	0.05	0.01	,18	3.920	0.001	2.8
Support from Family	−0.61	0.02	−,12	−2.466	0.024	1.4
Enabling and Partnership	−0.29	0.06	−,22	−4.102	0.000	3.5

2.6.4. Model that explains financial needs of families

The number of financial needs for families ("Financial Needs" subscale in FNS) was used as the dependent variable in this model. Four factors characterising children with cerebral palsy (GMFCS level, CFCS level, socialisation, the number of comorbidities), six factors characterising families (respondent's education level, employment, family income level, the perceived stress level of the child's primary caretaker, family and informal support), and eight factors characterising rehabilitation services (five MOPC sections, access to rehabilitation services in the place of residence, the regularity of receiving the rehabilitation services and professional support) were used as independent variables in the initial model.

The final model explained 53% (adjusted $R^2 = 0.53$) of variance of financial needs of families. The end-model and the unique contribution of each independent variable that had a statistically significant impact on the total number of financial needs for families are presented in table 2.11.

Table 2.11

Multiple regression model explaining financial needs for families

Regression model: **F(7,233) = 34.29; p = 0.000**						
Variable	B	SE	β	t	p	% of unique contribution
GMFCS level	0.34	0.06	,28	5.244	0.000	5.8
Number of comorbidities	0.14	0.05	,12	2.206	0.046	0.9
Employed vs not employed	0.63	0.16	,20	3.936	0.000	3.1
Income level						10.8
low vs high	1.96	0.29	,45	6.498	0.000	
average vs high	0.77	0.23	,17	2.595	0.017	
Enabling and Partnership	−0.273	0.06	−,21	−4.012	0.000	3.5
Support from Family	−0.09	0.02	−,17	−3.294	0.002	2.4

2.6.5. Model that explains family needs for information

The number of family needs for information ("Needs for Information" subscale in FNS) was used as the dependent variable in this model. Five factors characterising children with cerebral palsy (GMFCS level, CFCS level, socialisation, overall health condition, the number of comorbidities), six factors characterising families (respondent’s education level, employment, family income level, the perceived stress level of the child’s primary caretaker, family and informal support), and five factors characterising rehabilitation services (four MOPC sections, and professional support) were used as independent variables in the initial model.

The final model explained 23% ($R^2 = 0.23$) of variance of family needs for information. The final model and the unique influence of each independent variable that had a statistically significant impact on the total number of family needs for information are depicted in table 2.12.

Table 2.12

Multiple regression model explaining family needs for information

Regression model: **F(6,233) = 12.23; p = 0.000**						
Variable	B	SE	β	t	p	% of unique contribution
CFCS level	0.02	0.01	,17	2.865	0,005	2.5
Income level						3.5
low vs high	0.12	0.03	,28	3.280	0,001	
average vs high	0.10	0.03	,26	3.122	0,002	
Providing General Information	−0.03	0.01	−,16	−2.637	0,009	2.1
Formal support	−0.02	0.01	−,20	−3.218	0,001	3.2
Support from Family	−0.01	0.02	−,17	−2.618	0,009	2.0

3. DISCUSSION

3.1. Characteristics of the research group

The research engaged families who at the time of obtaining data cared for a child diagnosed with cerebral palsy at the age of two to seven years. The research did not focus on families with younger children because cerebral palsy is diagnosed during the first year only in about 50% of cases, while by the age of two it is diagnosed in 95% of cases, and the health problems related with brain damage have already been manifested (Granild-Jensen et al., 2015).

The goal of the research was to learn about the needs of families living in Latvia and identify the factors influencing these needs, therefore the authors of the research wanted to address all families which have children diagnosed with cerebral palsy at preschool age and who permanently reside in Latvia. As Latvia does not have a unified register of patients with cerebral palsy, information about the number of the respective families living in Latvia was based on information provided by the State Medical Commission for the Assessment of Health Condition and Working Ability, revealing that there were 264 children registered in Latvia who have been given the status of disabled based on ICD G80 code (cerebral palsy) and who were born between 2004 and 2010. The research engaged 234 families which is 88.6% of all potential families. Among the families included in the research 84 families or 36% lived in Riga, 89 families (38%) in other Latvian city, 61 families (26%) in a rural territory. Such a distribution of places of residence allows to assume that comprehensive information has been obtained about the needs and factors affecting families living in Latvia and raising preschool children with cerebral palsy.

Questionnaires were selected as the method of obtaining data and like in other similar studies (Farmer et al., 2004; Almasri, O'Neil & Palisano, 2014;

Hodgetts, Zwaigenbaum & Nicholas, 2015), the child's primary caretaker was invited to represent the family in the research. In our research families were mostly represented by mothers. Also in other studies about needs of families with children with developmental disorders respondents were mostly mothers (Palisano et al., 2010; Chiu, Turnbull & Summers, 2013; Hodgetts, Zwaigenbaum & Nicholas, 2015). 18% of respondents said that they were raising children on their own, but the majority was married or living with a permanent partner.

Analysing the education level of the child's primary caretaker, it was discovered that just 20 parents (8.5%) had elementary education, and 92 parents (39.3%) had higher education. These data relate to the overall distribution of education level among Latvian residents – the statistics for 2013 show that 40.7% of Latvian residents aged 30–34 had higher education (Central Statistical Bureau, 2013).

A notable fact is that just half of our respondents were employed during the time of obtaining data. In other studies employment of primary caretakers of children with developmental disorders has been higher. In studies conducted in North America it varied from 62% to 71% (Almasri et al., 2011; Caicedo, 2014), while data on nine European cities reveal that 85% of primary caretakers of children with cerebral palsy are employed (Parkes et al., 2011). Possibly, lower employment among our research participants can be explained with the fact that our research included families with younger children than other studies where the age scope of children with cerebral palsy was broader. However, it cannot be excluded that the low employment is related with social and economic factors characteristic of our region.

Employment and family income level are marked as important factors influencing family needs, therefore the questionnaire developed by the authors of the research had two questions to learn more about the family's financial situation. In the 17th question of the questionnaire respondents were asked to reveal the family's average monthly income, marking one of the four given answers. Majority (136 respondents or 58%) said that the family's monthly income was EUR 420-839. Almost one fifth of respondents said that the family's monthly income was lower than EUR 420, while 24% said the income was above EUR 840. Compared the obtained data with the data of the Central Statistical Bureau data on disposable household income in 2013, which was EUR 837.80 on average (Central Statistical Bureau, 2013), it can be concluded that for most of the families with preschool children with cerebral palsy income is lower than average in Latvian households. Such an outcome is logical because in half of the families only one of the parents was employed.

As we did not obtain information about the number of family members in households, then we concluded that total monthly income does not provide full information about the financial situation in families. Therefore, identifying factors influencing family needs, we used the 16th question in the questionnaire to characterise the financial situation in families where respondents provided their subjective opinion about the family income level, describing it as "rather low" (18.8%), "average" (67.1%) or "rather high" (14.1%).

Slightly more than half of children with cerebral palsy attended a preschool or day centre for children with special needs, but 95 children (40.6%) had not yet started attending a preschool. Some of the parents said that they do not have any appropriate preschool in their vicinity, while other believed that the child was not yet independent enough to attend a preschool or it was not possible due to the health condition – a large part of respondents assessed the health condition of their child as "rather poor".

Even though it was not the goal of this study to find epidemiological data, still, significant information was obtained about children diagnosed with cerebral palsy that had not been collected before. The information reveals that, like in other countries, cerebral palsy is slightly more often recorded for boys (55.6%) and the spastic type of cerebral palsy is more common (79.9%).

Dyskinetic cerebral palsy was found in 10.7% of children which is slightly lower than average in Europe – in Sweden dyskinetic form prevalence in cerebral palsy population is 16% (Himmelmann & Uvebrant, 2014), but in data on eight European countries show 14.4% (Bax, Tydeman & Flodmark, 2006). The mixed type of cerebral palsy was recorded in children more often (5.6%) than average in Europe (Bax, Tydeman & Flodmark, 2006). The above-mentioned differences possibly are related with different diagnostics approaches in different countries (Pakula, Braun & Yeargin-Allsopp, 2009). Assessing mobility limitations of the children included in the research we discovered that 53% of children are able to walk independently, 18% were walking with assistance, while 29% of children were not able to move independently or their mobility was not functionally significant. Such distribution of motor disabilities related with the overall trends in the cerebral palsy population – systematic meta-analysis of literature conducted by Novak and colleagues show that 58% of children diagnosed with cerebral palsy can walk without any assistive devices, 11% move using assistive devices, 14% use a wheelchair, and for 17% of children independent movement is not possible (Novak et al., 2012). Also distribution of health disorders related with brain damage among the studied children with cerebral palsy was similar to the average in the population (McMahon, Pruitt & Vargus-Adams, 2015). Thus, our data prove that the assumption that distribution of types of cerebral palsy and characteristic features related with the diagnosed cerebral palsy in Latvia are similar to that in other European countries.

3.2. Results of “Family Needs Survey”

According to the results of "Family Needs Survey", the biggest share of needs was pointed out in the "Needs for Information" subscale. More than half of respondents have given affirmative answers to all statements in this section.

There is a similar trend also in other studies where needs of families with children with functional disabilities are viewed (Ellis et al., 2002; Farmer et al., 2004; Nitta et al., 2005; Palisano et al., 2010, Hodgetts, Zwaigenbaum & Nicholas, 2015; Piškuret al., 2017). It might mean that the majority of families who are raising children with developmental disorders feel that they lack information about the child's disorders, ways to promote development, services and future perspectives, and service providers should think how to improve provision of information to these families. Still, Palisano and colleagues, observing a similar trend in their study made an assumption that the large number of "needs for information" is possibly related with the opinion of the surveyed parents that "there is never too much information" rather than true lack of information (Palisano et al., 2010). Despite this assumption, health care providers should make sure that families have received professional answers to their questions. It is especially important now when internet is broadly used to obtain information, but it often provides confusing, unsubstantiated information about the child's treatment and rehabilitation opportunities (Pehora et al., 2015).

In our study a large number of respondents pointed out that they need information about services that are available for their child with cerebral palsy (88.9%) and services that they would need in the future (85%). Data published by other authors are slightly different. Just 54% of parents surveyed by Farmer, 63% of parents surveyed by Ellis and 59% of parents polled by Palisano mentioned that they need information about the presently available services, while 74%, 78% and 68% of parents, respectively, were interested about the future services (Ellis et al., 2002; Farmer et al., 2004; Palisano et al., 2010). Such differences show that families living in Latvia are less informed about services available for their children with developmental disorders and service providers should make sure that the family is informed about issues important to it.

Families surveyed by us more often than families surveyed by other researchers said that they wish to obtain information about their child's disorders, as well as about training and education opportunities for the child. Possibly such increased interest can be explained with the peculiarities of the age of the children. Our research included preschool children, while other authors studied families with children of different ages, including school age. It is noted that the younger the child, the higher parents' interest in all kinds of information. Young parents are scared and unconfident, they have not yet got used to the new situation and supply of services, they are looking for every opportunity to promote the child's development (Palisano et al., 2010).

The next most important area in which most of the families expressed wish for additional support was needs related with community services (treatment, rehabilitation, preschools, etc.) and financial support. Such a result is no surprise. It is well-known that cerebral palsy is an "expensive" disorder and its costs may reach EUR 900,000 throughout the lifetime (Kruse et al., 2009). Availability of services, financial challenges for families who are raising children with cerebral palsy are much higher than for other families with children of similar age (Kancherla et al., 2012). As it is often a case, also in our research group, that one parent is not working any more or is working part-time, financial challenges are even higher.

More than half (61.1%) of the families said that they need help to ensure rehabilitation services for the child, while one third needed assistance in finding a preschool or babysitter. It is alarming that 73% of respondents said that the family needs help to coordinate medical, social and education services. It should be noted that there was a similar discovery made in a survey commissioned by the ombudsman, "Efficiency of Rehabilitation of Children with Disabilities in Latvia: Socio-anthropological Aspect", which concluded that "the planning system in Latvia is weighty and bureaucratic", and "activities of state and municipal authorities and medical professionals are reactive, not proactive" ("Bērnu ar invaliditāti rehabilitācijas efektivitāte Latvijā: sociālantopoloģiskais aspekts", 2016). The Latvian legislation provides for coordinated care for persons with functional disorders. So, for example, Cabinet of Ministers regulations No.9 on an individual rehabilitation plan for a person with predictable disability and a person with disability provides for a coordinated development of a program for support and integration of a person with functional disorders. Also some local governments offer services to their residents, aiming to provide coordinated service. For example, Riga already for several years has been implementing service "Social rehabilitation programs for children with functional limitations", aiming to "promote renewal or improvement of a person's social functioning abilities, resuming the person's the social status and integration into the society, including in the education system" (Riga City Council welfare department).

Unfortunately, the study results show that, despite the fact that in recent years the support provided to families with children with functional disabilities by local governments and the Latvian state has grown, as it is provided in the legislation, the range of the offered services is insufficient and coordination of these services is still inefficient. It should be noted that in countries with historically stable social support system families less often point at the necessity related with coordinated provision of medical, social and educational services (Farmer et al., 2004; Palisano et al., 2010; Almasri et al., 2011; Hodgetts, Zwaigenbaum & Nicholas,2015).

It is an established fact that as the child with functioning disorders grows, the need for financial support also grows (Almasri et al., 2011). As long as the child is little, the child can be carried in standardized baby strollers, using standard baby chair for support. During this period, parents seldom think about the necessity for walking devices or wheelchairs adapted to the size of the child. As the child grows, there is a necessity for special assistive devices to promote the child's independence or prevent medical complications. The issue of adapting, modifying the house is also on the agenda, requiring financial expenses. As in the families we surveyed children were up to the age of seven, a comparatively small number of families said that they would need financial assistance for house modification. Still, more than half of respondents needed financial support for special equipment or assistive devices. Even though the technical assistive devices necessary for functioning are government-funded, sometimes parents have to buy them for their own resources. For, example, if a child needs special positioning chair for supported seating, the child is entitled to receive such one chair under the government program. However, if a child is attending a preschool, the child needs two such chairs – one at home and one at school. Unfortunately, budgets of educational establishments do not allow to purchase such equipment. Therefore parents have to use their own resources to buy a second chair that can be used at school. Sometimes parents are not satisfied with the quality of the government-funded equipment or the long waiting time – and they purchase the device for their own resources also in these cases. It should be noted that similar need for financial support for purchase of assistive devices was voiced by parents surveyed by Nitta in Japan and parents surveyed by Wang in China (Nitta et al., 2005; Wang & Michaels, 2010). Meanwhile, in Farmer's and Palisano's surveys in the US such needs were marked just by 19% and 34% of parents, respectively (Farmer et al., 2004; Palisano et al., 2010).

It is not surprising that the majority of families noted the necessity for financial support to cover expenses related with the child's treatment and rehabilitation. Rehabilitation within the government-funded health care system is available to a limited amount and intensity, therefore, in addition to that, families want to undergo therapies also in paid services sector. Quite often, looking for ways to improve the health condition of their child, parents choose to use medical services that are not included in the basket of services funded by the government or look for medical treatment or rehabilitation opportunities abroad.

A large part of the surveyed families said that they need not only financial, but also moral and psychological support. Most of respondents said that they would like to meet with families with similar children more often, and read about families with similar problems. During interviews parents said that conversations with parents who are facing similar problems and challenges, and positive examples are what help most to cope with the situation at most difficult times. Also, almost half of respondents said that they would like to receive regular professional psychological support.

As taking care of the sick child takes a large part of the day, and half of the children did not attend a preschool, it is not a surprise that the majority of the surveyed parents would like to have more time to themselves. Such type of needs is marked as important also in reports published by other authors (Perrin, Lewkowicz & Young, 2000; Ellis et al., 2002; Nitta et al., 2005; Wang & Michaels, 2010).

Like in the research by Palisano and colleagues, just a small number of respondents noted the needs that are related with family functioning (Palisano et al., 2010). It is possible that families indeed do not need such assistance. Still, it cannot be excluded that parents are not aware or are not admitting such needs. It is believed that parents who have a child with developmental orders or a chronic illness more often think about how to promote the child's development and less focus on family needs or do not consider them as needs which might be a reason for elevated stress and families breaking apart (Graves & Hayes, 1996).

Just a small part of respondents marked that they need help in explaining the condition of their child to other people which relates with information published by other authors (Nitta et al., 2005; Palisano et al., 2010). Still, at least one third of respondents said that they need assistance to explain the condition of their child to professionals (preschool teachers and medics). Such a result means that, despite the active integration processes in the country, education and even health care specialists are not well informed and prepared for work with children with functioning limitations.

In general, we can conclude that families living in Latvia and raising children with cerebral palsy have similar needs as families living in other countries. However, it should be marked that our families especially need information about availability of services, and assistance in coordination of medical and rehabilitation services. It still suggests that Latvia does not have an efficient system that would ensure comprehensive and coordinated support to families who are raising children with developmental disorders.

3.3. Correlation between factors characterising children with cerebral palsy and family needs

Based on a comprehensive study of literature on the impact of factors characterising children on family needs, the research included and studied the following factors characterising children with cerebral palsy: the child's age, communication function, motor function, the number of morbidities, assessment of overall health condition and socialisation.

The publications note that there is a correlation between the age of the child with functioning disorders and the number of family needs – lower age is related with increased number of overall family needs (Ellis et al., 2002; Ueda et al., 2013). Still, our research did not find such a correlation, therefore we did not include the child's age in further analysis to identify the factors influencing family needs. Possibly, such a result can be explained with the age of the research group – our research included preschool children, so the total age scope was small, while other studied referred to families with children of different ages.

Other reviewed factors characterising children with cerebral palsy were related with the total number of family needs and with the number of needs in all reviewed groups of needs and were included in the regression analysis as possible factors influencing family needs.

Literature sources name the child's functioning limitations and health condition as significant factors influencing family needs – the more distinct functioning limitations and complicated health disorders, the higher family needs (Sloper & Turner, 1992; Farmer et al., 2004; Nitta et al., 2005; Eddy & Engel, 2008; Palisano et al., 2010; Almasri, O'Neil & Palisano, 2014). Also, correlation analysis results in our research proved that there is such a correlation, still, the influence of these factors on the total number of family needs was not so convincing. Even though the level of the child's movement limitations was related with the total number of family needs, its unique impact on the total number of family needs was low. Still, the level of the child's mobility limitations was a significant factor influencing financial needs of families – families whose children were able to walk without any assistive devices marked lower needs for financial support compared to families whose children did not have such a possibility. The obtained data match with information published by other authors (Palisano et al., 2010; Almasri, O'Neil & Palisano, 2014). Meanwhile, in contrast to results found by Almasri and colleagues, the influence of the child's mobility limitation levels on family needs for services and support was not discovered in our research (Almasri, O'Neil & Palisano, 2014).

An unexpected result was the influence of the child's communication limitations to family needs for community services – families with children who had more distinct communication problems most often noted that they need assistance in finding and provision of medical, rehabilitation or education services. This factor turned out to be most significant of the identified factors characterising the child, family and services, with a strong unique impact on this type of family needs. The child’s communication limitations also affected the family needs for information – more distinct communication disorders for the child increased the number of family needs in this type of needs. It has been established that cognitive and behavioural disorders in children are factors that increase the family needs (Almasri,O’Neil & Palisano, 2014; Hodgetts, 2015) while children with distinctive communication problems often have cognitive limitations and limited socialisation (Mei et al., 2015; Lipscombe et al., 2016). Considering the child’s age, the cognitive level of the children included in the research was not evaluated. Still, an assumption could be made that children with distinctive communication problems had more distinct cognitive limitations that possibly determined higher family needs for services and information.

Data analysis in our research discovered that as the number of comorbidities associated with brain damage grows, the total family needs increases, as well as needs for support and financial needs, and this factor had a significant role on family needs in the above-mentioned types of needs. Nevertheless, even though the overall characteristics of the child’s health condition was related with several areas of family needs, its influence was not significant in any of them in particular.

Even though results analysis revealed a weak correlation between the child’s socialisation and the total number of family needs and the number of needs in separate areas, still the child’s socialisations turned out to be a significant factor affecting family needs only in needs for community services. If the child did not attend a preschool of day centre, the family needs for community services rose.

3.4. Correlation between factors characterising family and family needs

The following factors characterising families that might influence family needs were studied in our research: age, education, employment of the child's primary caretaker, the family status and perceived stress level, the number of children in the family, the family income level, the place of residence, support of family and friends.

Even though literature sources suggest that older mothers voiced higher need for support (Ziviani et al., 2014; Hodgetts, Zwaigenbaum & Nicholas, 2015), our research did not reveal such correlation. The age of the primary caretaker was not related with the total number of family needs, or with the number of needs in particular groups of needs, therefore this factors was not included in the regression analysis.

Ziviani and colleagues in their research noted that single parents voiced a higher number of needs (Ziviani et al., 2014), while our research did not confirm this correlation, therefore the family status was not used in further analysis.

Nevertheless, the support provided by closest family members was a very significant factor affecting family needs – as the child's primary caretaker received support and assistance from other family members, the number of family needs declined. This was the only factors used in the analysis with a significant impact on the total number of family needs and the number of needs in all reviewed groups of needs. Also other researchers confirmed that families that have good and supporting mutual relations are more successful in solving issues that are related with the care and treatment of the sick child, and these families less often need "external" support (Glenn et al., 2009; Palisano et al., 2010). This is valuable information to service providers. Service providers should be aware that in cases when the service is received by a family that lacks this internal support, possibly, there is a greater need for services, information, social and financial support.

The education level of respondents in general was not a significant factor influencing family needs. The only impact was discovered on the family needs for support – elementary education was a factor increasing family needs just in this area. The literature sources provide controversial information on the influence of parents' education level on family needs – Bailey and Ueda in their studies relate lower education level with increased family needs, while studies of Farmer, Palisano and Almasri did not reveal such relation (Bailey et al., 1999; Ueda et al., 2013, Farmer et al., 2004, Palisano et al., 2010; Almasri, O'Neil & Palisano, 2014).

The perceived stress level of the child's primary caretaker turned out to be a significant factor affecting family needs. Higher perceived stress level increased the total number of family needs and the number of needs for community services and support. Heightened stress level in parents is related with higher necessity for support also in literature sources (Glenn et al., 2009; Cantwell, Muldoon & Gallagher, 2014).

The studies noted that a bigger number of children in the family is related with a larger number of needs, especially the need for additional financial support (Lindley & Mark, 2010). Even though in our study families with two or more children voiced higher need for financial support than families with one child, this factor still did not have a significant impact on this type of needs.

If there is a child with health and functioning disorders in a family, then availability of different health and social services becomes important. Farmer and Almasri in their studies discovered that families who live in cities where health, social care and educational institutions are more easily accessible in general mark lower needs than families living in more distant regions (Farmer et al., 2004, Almasri, O'Neil & Palisano, 2014). Also, our research revealed a similar trend – families living in Riga noted lower needs for community services than families living in other cities or rural territories. Still, the influence of this factor on this area of needs was not confirmed. In our research neither the place of residence, nor the number of children in the family had a significant impact on family needs.

Among most significant factors reducing family needs are higher family's socio-economic status and higher income (Farmer et al., 2004; Almasri et al., 2011; Ueda et al., 2013; Almasri, O'Neil & Palisano, 2014). This information is also confirmed in our research. Medium and, even more so, low family income level increased the total number of family needs, and the number of family needs for community services, information and financial support. The only type of needs reviewed in the study that was not affected by the income level was family needs for support – equal wish for formal and informal support was voiced by those respondents whose family income level was assessed as high and those who assessed their income level as medium or even low.

Even though the overall financial situation of families can be affected by the fact whether all adult family members are employed, in our study correlation between the factor that described employment of the child's primary caretaker and the family income level was weak. Still, employment of the child's primary caretaker by itself was a significant factor reducing family needs. If the child's primary caretaker was employed, the total number of family needs as well as financial needs and needs for services declined.

3.5. Correlation between factors characterising rehabilitation services and family needs

The following factors characterising rehabilitation services were studied in the research: availability of rehabilitation services in the place of residents, the procedure of receiving rehabilitation services, the support received from professionals, compliance of the rehabilitation services to the family-centred care provision principles "Respectful and Supporting Care", "Enabling and Partnership", "Co-ordinated and Comprehensive Care", "Provision of General Information" and "Provision of Specific Information".

Surprisingly, but in contrast to information published by Almasri and colleagues (Almasri, O'Neil & Palisano, 2014), neither availability of rehabilitation services at the place of residents, nor the regularity of receiving rehabilitation services were factors that affected the family needs of our respondents. Even though the surveyed families who noted that rehabilitation services are not available at the place of their residence had more financial needs and more needs for community services, still, it was not a factor significantly affecting these needs. A similar trend was observed in relation to the way the rehabilitation services were received. Families whose children were able to receive rehabilitation services on a regular basis voiced lower needs for financial assistance and community services than families whose children received rehabilitation services in a form of courses. Still, the influence of this factor on the number of financial and community services needs was not significant. Meanwhile, the above-mentioned factors characterising rehabilitation services were not related with the total number of family needs and needs for information and support at all. Support received from professionals, however, turned out to be a significant factor reducing needs. Families who said that they feel huge support and assistance from professionals who work with their children noted a lower number of total needs and, in this case, families had lower needs for community services, support, information and financial assistance. Higher support from professionals was a significant factor reducing total family needs and needs for information and support. Also, there was a positive reducing effect on family needs if the family noted that the received services complied with the principles of family-centred care.

Especially the role of the principle "Enabling and Partnership" should be underscored. Providing services based on cooperation and partnership principles, i.e., engaging the family in decision making as an equal partners, it is possible to significantly reduce the overall family needs and needs for support, services and additional financing. Following the principle "Provision of General Information" was an important factor to reduce needs for information. Our results match with the reports by Palisano and Almasri on the positive impact of family-centred care on reducing family needs in families who are raising children with cerebral palsy (Palisano et al., 2010; Almasri, O'Neil & Palisano, 2014).

It can be concluded that the most important factors reducing family needs were those related with attitude – the way professionals, including health care specialists, communicate with families, how successfully they develop cooperation and provide support. The impact of availability of services at the place of residence and regularity of services on the type and number of family needs was not convincing.

3.6. Analysis of factors explaining needs of families of children with cerebral palsy

The method of multiple linear regression was used to determine the factors influencing family needs. As it is reported that the factors affecting family needs vary depending on the type of needs (Almasri, O'Neil & Palisano, 2014; Hodgetts, Zwaigenbaum & Nicholas 2015), five family needs models were distinguished and studied to identify factors affecting family needs.

3.6.1. Analysis of factors explaining overall family needs

The developed regression final model with nine independent variables explained 61% of variances of overall family needs. In this model, the strongest factor influencing family needs was the family's own internal support that explained 8.2% outcome. As reported earlier, it is significant information to service providers, including providers of medical and rehabilitation services who would have to pay increased attention to cases if services are given to a child whose caretaker is not supported by other family members.

It is interesting that the second most important factor explaining overall family needs was reception of services based on family-centred care principle "Enabling and Partnership" while the third most important factor was support provided by professionals. Thus, support of service providers and following family-centred care principles could leave a positive impact on reducing overall family needs. This again is significant information for service providers that proves importance of the way the family is engaged in treatment and rehabilitation processes and of the skills of services providers to communicate with the client and cooperate. These factors were more important in reducing family needs than socio-economic factors – the family income level and employment of the child's primary caretaker.

It was surprising that factors related with the child's health condition, even though they were important in explaining overall family needs, had a low individual impact. Thus, the overall number of morbidities explained 2.5%, while the child's mobility limitations explained just 0.7% changes in overall family needs. A high perceived stress level of the child's primary caretaker turned out to be an important factor increasing overall family needs, with a higher unique impact than socio-economic factors and factors related with the child's health condition.

3.6.2. Analysis of factors explaining family needs for support

The established model with six independent variables explained 44% variances of family needs for support. It is not a surprise that the factor with the biggest unique impact (13.9%) was the support of the family itself – support and assistance received from the closest family members significantly reduce the necessity to look for additional support. It is also important to note the influence of professional support. Support of service providers (unique impact – 4.2%) and following family-centred care principle "Enabling and Partnership" (unique impact – 4.5%) were significant factors, reducing family needs for support. The next most important factor influencing family needs for support was the number of comorbidities – as this number grew, the needs for support also increased. Surprisingly, this was the only child-related factor that had an impact on family needs for support.

Such factors as the education level and perceived stress level of the child's primary caretaker had a similar impact on family needs. High perceived stress level and elementary education were significant factors increasing family needs for support. It is also interesting that lower education level of parents so far had not been related with needs for additional support (Almasri, O'Neil & Palisano, 2014; Hodgetts, Zwaigenbaum & Nicholas, 2015), while correlation between elevated stress levels and increased necessity for support has been revealed also in other studies (Dyson, 1997; Farmer et al., 2004; Glenn et al., 2008).

3.6.3. Analysis of factors explaining family's financial needs

The final model that explained 53% of variances of financial needs of families included six factors – two factors characterising children with cerebral palsy, three factors characterising the family, and one factor characterising the service providers. It is not surprising that the factor with the highest unique impact (10.8%) was family's income level – high income level was identified as a strong factor reducing family's financial needs. Impact of employment of the child's primary caretaker is also understandable (3.1%) – if any of the family members is not employed, it reduces the family's income, and financial needs might grow. The third factor characterising the family and reducing its financial needs was the family's internal support – higher support of family members significantly reduced the family's financial needs.

The second most significant factor with 5.8% unique impact on family's financial needs was the level of the child's mobility limitations. This result is not surprising, either. In a situation when the child's mobility limitations are significant, medical treatment and rehabilitation costs grow, there are higher costs for purchase of assistive equipment and modification of the home environment. The level of the child's mobility limitations is identified as a significant factor influencing the family's financial needs also in other studies (Palisano et al., 2010; Almasri, O'Neil & Palisano, 2014). Another factor characterising children with cerebral palsy with a significant impact on increase of the family needs was the number of comorbidities – a larger number of comorbidities increased the family's financial needs, still in the developed model the unique impact of this factor was low.

A discovery that provision of services based on family-centred care principles can reduce the family's financial needs was a surprise to some extent. Even though the recent results of the study conducted by Almasri also reveals the positive impact of family-centred services on meeting financial needs of families (Almasri, O'Neil & Palisano, 2014). Families receiving services based on family-centred care principles, assumingly, are more satisfied with the service and, possibly, less often look for paid services, thus, reducing their financial expenses.

3.6.4. Analysis of factors explaining family needs for community services

The developed regression final model consisted of seven variables and explained 52% of variances of family needs for community services. In this model, the level of the child's communication abilities turned out to be the factor with the highest unique impact (5.8%) – families with children with more distinct communication limitations showed higher need for community services. Surprisingly, the child's mobility limitations did not have an impact on family's needs for community services. Our results do not match results published by other authors where functional limitations of the child, including mobility disorders, were a significant fact affecting family needs for services (Farmer et al., 2004; Palisano et al., 2010; Almasri, O'Neil & Palisano, 2014). Obviously, rehabilitation and education services for children with motor disorders in Latvia are more available and better developed than services for children who, in addition, have distinctive communication limitations that often are combined with cognitive disorders, thus, the need for specific education and rehabilitation programmes increases.

The second most important factor explaining family needs for services in this model was socialisation of the child. Attendance of a preschool or day centre was a significant factor, reducing the needs for services. The third most important factor with 3.5% unique impact was following the family-centred care principle "Enabling and Partnership". Obviously, like in the context of the financial needs, families who receive services based on family-centred care principles are more satisfied with the current services and there is lower need for new services. Publications of other authors also note that family-centred care reduces family needs for services (Palisano et al., 2010; Almasri, O'Neil & Palisano, 2014).

It is interesting that in this model, the perceived stress level of the child's primary care taker was of a higher unique impact on family needs for services than the caretaker's employment or family's income level. Employment and family's financial situation often are identified as factors that influence the family needs for community services in cases when families are raising children with developmental disorders (Farmer et al., 2004; Palisano et al., 2010; Hodgetts, Zwaigenbaum & Nicholas, 2015), while we did not find information about the impact of the caretaker's stress level on this type of needs. Possibly, it is harder for persons with higher stress level to organize their everyday activities and set priorities, and it has a negative effect on the quality of the person's life, laying obstacles for optimum planning and organization of the tasks (Glenn et al., 2009; Wu et al., 2014).

As it was mentioned earlier, the only identified factor affecting family needs with a significant impact on all types of family needs was the support provided by the family itself. Also in this case, higher support from family members was a significant factor reducing family needs for community services, even though its unique impact was lower than that of other factors included in the model.

3.6.5. Analysis of factors explaining family needs for information

The final model explained 23% of variances of family needs for information. In this model the factors influencing family needs most were family's income level and professional support. As family income level increased and higher support from professionals involved in the child's treatment and education was received, the need for information reduced. Need for information also reduced if services were provided based on family-centred care principle "Provision of General Information", and when the child's primary caretaker received support from other family members.

The only child-related factor that influenced the family needs for information were the child's communication – distinct communication limitations for the child increased family needs for information.

The low value of determination coefficient suggests that the study failed to identify the factors that more importantly explained this type of family needs. The low value of determination coefficient possibly is related with peculiarities of data analysis. As the score value in FNS subscale of needs for information did not match the normal distribution, logarithmic equation was applied, that, possibly, affected the result of the regression analysis.

3.6.6. Summary of factors explaining family needs

In our research, six factors characterising children with cerebral palsy, ten factors characterising families and nine factors characterising rehabilitation services were reviewed as possible factors influencing family needs, but only one of the analysed factors – the family's internal support – was identified as a significant factor influencing family needs in all areas of needs. As the child's primary caretaker received support from other family members, other needs considerably reduced.

Like in the reports of other authors (Palisano et al., 2010, Almasri, O'Neil & Palisano, 2014, Hodgets, Zwaigenbaum & Nicholas, 2015), also our research revealed that factors reducing family needs included such socio-economic factors as the family's income level that was a significant factor affecting family needs in four types of needs, and employment of the child's primary caretaker with an impact on three types of family needs. The impact of factors related with the child's health condition was less important – a larger number of comorbidities was a factor increasing family needs in three areas of needs, but its unique impact was low. Mobility and communication limitations were factors increasing family needs only in two areas of needs – distinctive communication limitation for the child increased family needs for community services and information, while severe mobility limitations increased financial needs and overall family needs.

The perceived stress level of the child's primary caretaker turned out to be a significant factor affecting family needs in three areas of needs – higher perceived stress level increased the overall family needs and needs for community services and support.

The above-mentioned factors are unique, individual and in most cases cannot be directly influenced. Service providers who work with families raising a preschool child with cerebral palsy should consider the impact of the above-mentioned factors on family needs and should pay additional attention to families with potentially higher risk of needs.

Analysis of the research results also revealed a significant impact of those factors that directly depend on service providers. Thus, provision of rehabilitation services based on family-centred care principle "Enabling and Partnership" was a significant factor reducing family needs in four areas of needs – overall family needs, needs for support, services and financial support. Meanwhile, if a family received bigger support from professionals who work with the child or the family, it was a significant factor reducing family needs in three areas of needs.

In conclusion, the most important factors affecting needs of families living in Latvia are related with the socio-economic situation and support of peers – family members or professionals who work with the family. Limitations of the child's functioning and health disorders were factors influencing family needs to a lower extent.

3.7. Methodological analysis and limitations of the research

In order to achieve the objective of the research, analytical cross-sectional design was selected for the study. Thus, information about families living in Latvia and raising preschool children diagnosed with cerebral palsy, family needs and factors affecting them was obtained during a certain period of time. In order to claim that the information obtained during the study can be generalised also in relation to another time period, data should be obtained repeatedly, but this has not been planned. Thus, information obtained about the needs of families living in Latvia and factors affecting them, should be assessed and interpreted with caution, not excluding possible changes in time.

Family needs were identified, using a standardised questionnaire "Family Needs Survey" that during the period of obtaining the data was the most recognized and broadly used questionnaire for identifying family needs. The questionnaire has been developed to learn about needs of those families who are raising preschool children with development disorders. Still, the questionnaire has been developed several dozens of years ago and, even though its modified version was used to obtain the data, it is still possible that not all needs that families living in Latvia and raising children with cerebral palsy might have, have been identified. The advantage of use of a standardized questionnaires is simplicity in obtaining data and an opportunity to analyse these data by using quantitative data analysis methods. Still, such a way of obtaining data does not allow to study the problem thoroughly, therefore, it would be recommended to conduct more thorough study of the obtained data, using qualitative methods for data extraction and analysis.

The possible factors influencing family needs were identified based on comprehensive study of literature sources and factors that may affect family needs in cases when families take care of children with cerebral palsy. Needs of families raising children with developmental disorders have been studied broadly, but, during the preparation phase, we did not manage to find sources that have studied family needs in the nearest geopolitical region with similar historical and socio-economic background. Thus, possibly, we did not manage to identify the type of needs or possible factors influencing these needs that are unique for our region. This is proved in the multiple linear regression analysis – the final models explained 23%–61% changes in family needs. Thus, there could be other unpredicted and unidentified factors that might affect needs of the families living in Latvia. It would be more targeted approach to use the qualitative research design that would allow to understand the research problem more thoroughly and present a new hypothesis.

The factors affecting family needs were determined using multiple linear regression analysis method. Such analysis method was selected because it allows to study dependence of the features on a number of independent features, and the data obtained in the study met the requirements for conducting a multiple linear regression analysis. However, this type of analysis has its drawbacks. Even though we managed to study factors that might affect family needs and test their impact on stability of the regression models, still, some inaccuracies during the data obtaining and analysis process cannot be excluded. It is also established that not all independent variables have a direct impact on the dependent feature (Palisano et al., 2010), therefore, for deeper understanding of the research problem and construct, further studies should focus on indirect impact of the identified and possibly new factors.

CONCLUSIONS

1. Families of preschool children with cerebral palsy living in Latvia believe that they lack information about issues important for the family – especially about services available for children with cerebral palsy and education possibilities for those children.
2. The surveyed families feel that provision of rehabilitation services is insufficient and there are shortages in efficient coordination of rehabilitation, education and social services.
3. Results of the study reveal that the government funding is insufficient for treatment and rehabilitation of children with cerebral palsy – the majority of families need financial support to cover treatment and rehabilitation expenses.
4. Some of the surveyed families of children with cerebral palsy mark lack of psychological and moral support.
5. The research supports the hypothesis that needs of families of children with cerebral palsy are affected by factors characterising the family, the child with cerebral palsy and rehabilitation service providers, and the unique impact of these factors depend on the type of family needs. Based on the regression analysis models:
   - *overall needs* of families of children with cerebral palsy living in Latvia were best explained by support received from other family members. Further most important factors were family's income level, employment and perceived stress level of the child's primary caretaker, and the support received from professionals, as well as service provision based on enabling and partnership principles, and the number of comorbidities for the child. Meanwhile, the level of the child's mobility limitations explained these needs to a low extent.

- *needs for services* of families of children with cerebral palsy living in Latvia were best explained by the level of the child's socialisation, communication ability and perceived stress level of the child's primary caretaker, while they were slightly less explained by the family's income level, employment of the child's primary caretaker, support from other family members and service provision based on enabling and partnership principles.
- *financial needs* of families of children with cerebral palsy living in Latvia were best explained by such factors as the family's income level and the child's mobility limitations, while they were slightly less explained by employment of the child's primary caretaker, provision of services based on enabling and partnership principles and support from other family members, as well as the number of comorbidities.
- *needs for support* of families of children with cerebral palsy living in Latvia were best explained by the support from other family members, and slightly less explained by support received from professionals and provision of services based on enabling and partnership principles, the education level and perceived stress level of the child's primary caretaker, and the number of comorbidities for the child.
- *needs for information* were best explained by support from professionals and family members, provision of services based on principles on providing general information, the family's income level, and communication limitations for the child with cerebral palsy.

6. Some factors that explain needs of families living in Latvia have not been identified.
7. In general, the results of the research reveal that the most important factors affecting needs of families living in Latvia are related with the socio-economic situation, and support of peers and professionals.

Meanwhile, availability and regularity of rehabilitation services, limitations to the child's functioning and health disorders are factors affecting family needs to a lower extent.

PRACTICAL AND ORGANISATIONAL RECOMMENDATIONS

1. In order to ensure targeted and coordinated treatment and rehabilitation for children with cerebral palsy and ensure support to the whole family, Latvia should develop a system that would allow to coordinate the services necessary for the child's treatment and rehabilitation and provided by different institutions, and ensure the necessary support and information to the family. Such systemic support should be ensured since the moment the child is diagnosed with cerebral palsy.
2. Results of the research reveal the importance of the support provided by professionals, including rehabilitation professionals, in reducing family needs. Therefore, not only application of the respective medical technologies, but also human support to the child's caretakers and provision of services based on family-centred care principles are important. Education programmes of rehabilitation specialists should include courses that improve the abilities of specialists to provide psychological support and improve skills to implement family-centred approach to treatment and rehabilitation.
3. It is important for providers of medical and rehabilitation services, as well as education and social services to learn about the family's own internal support. If the child's primary caretaker has no support of its own family members, the family should receive increased attention and support.

4. As the results of the research point at problems in availability of rehabilitation and preschool education services to children with distinct communication disorders, rehabilitation programmes for children with cerebral palsy who, in addition to mobility limitations, have communication limitations should be developed.

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